

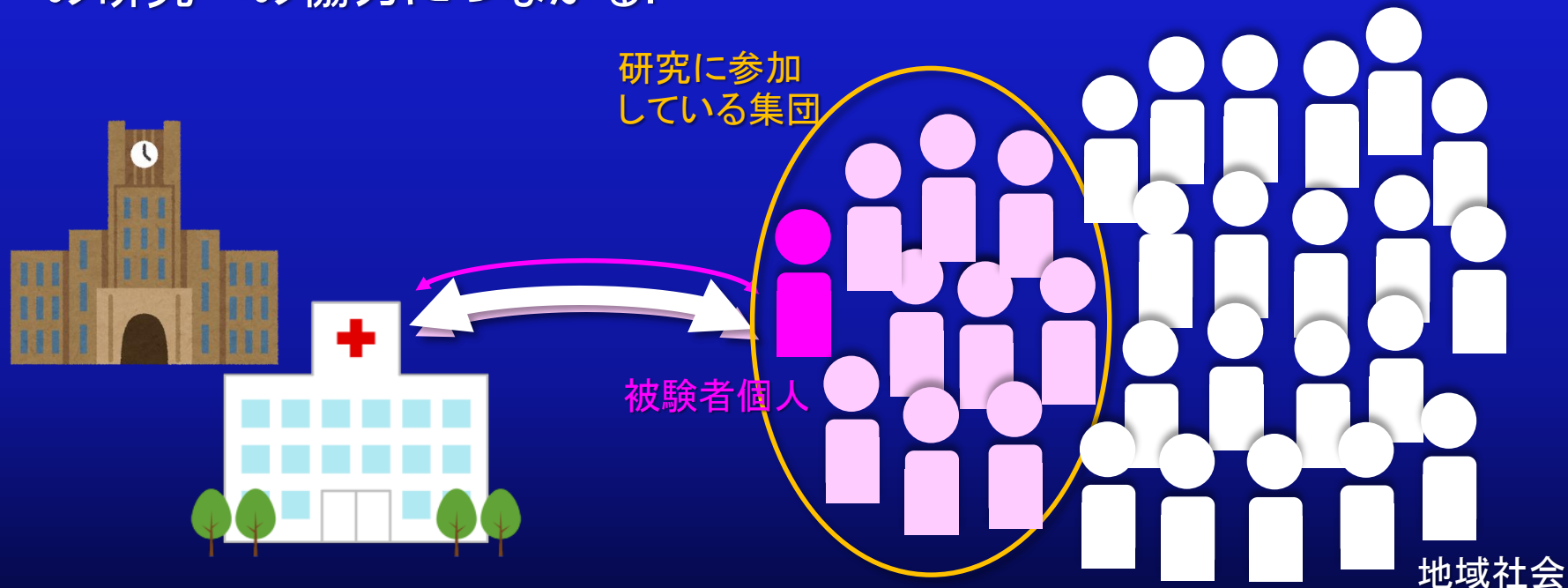
米国における認知症研究成果の 社会還元と啓発活動

東京大学大学院医学系研究科 神経病理学
同附属病院 早期・探索開発推進室

井原 涼子

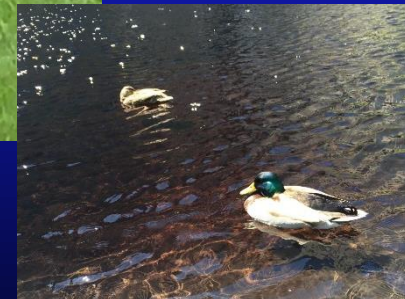
米国における研究とアウトリーチ活動

- ◆ 研究施設が地域社会に対して行う活動をアウトリーチという。
- ◆ 研究に参加している集団を対象とした活動，それを超えた地域社会を対象とした活動がある。
- ◆ 米国NIHに助成される研究機関Alzheimer's Disease Centerには，教育・アウトリーチを担当する部門を設けることが必須要件。
- ◆ 臨床研究の場が地域社会へ啓蒙（教育）を行うことは，地域住民の研究への協力につながる。



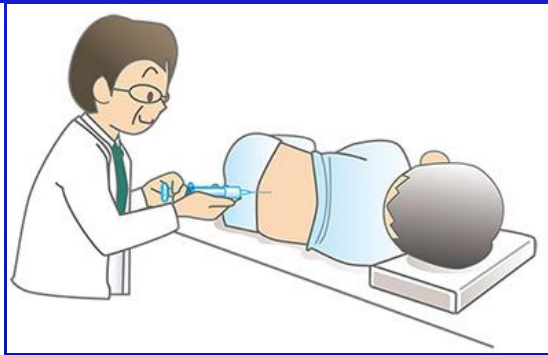
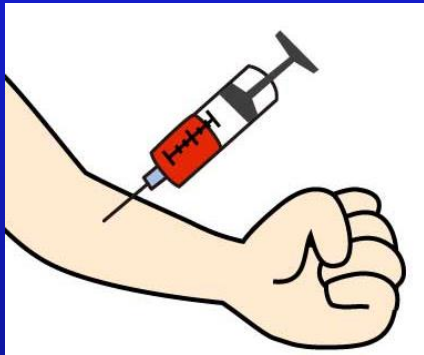
Knight Alzheimer's Disease Research Center

Washington University in St. Louis
Department of Neurology



Knight ADRCの特徴

- ◆ 国の大型研究助成を4つ受け、3つのコホート研究を施行.
- ◆ 約900人の被験者を抱える. 原則年1回評価に来訪.
- ◆ 約2/3が認知機能正常な健常者.
- ◆ 完全に研究の場としての位置づけ. 医療の提供は行わない.
- ◆ 研究で施行した検査は、被験者さんに個別の結果を返さない.



被験者さんへの結果の返却なし

希望があれば、
かかりつけ医に手紙

Knight ADRCの被験者さんとのコミュニケーション

- ◆ 3つの研究毎に年1回被験者ミーティングに招待
 - 研究の最新の成果を報告
 - 手順, 被験者の負担に関する疑問の解消
 - 関連した研究への勧誘
 - 被験者同士の交流の場としての意義
- ◆ 年4回最新の研究成果を報告するニュースレターを送付
- ◆ その他にホリデーカードなど



Memory & Aging Project Participant Meeting
(5/30/2015)
300人以上の被験者・家族が参加



UPDATE AS OF SEPTEMBER 30, 2015...

Number of ACS participants with longitudinal LPs ("Lovely Procedure")

	TOTAL	1 LP	2 LP	3 LP	4 LP	5 LP
# of participants	320	137	75	64	39	5

Incidence of post-LP headaches requiring blood patches in the ACS is very low and differs with age (as expected).

	NUMBER OF CSF COLLECTIONS	NUMBER REQUIRING BLOOD PATCHES	% REQUIRING BLOOD PATCHES
ALL ACS	663	23	3.5%
Age >60 yrs	379	7	1.8%
Age ≤ 60 yrs	284	16	5.6%

Adult Children Study Participant Meeting
(10/10/2015)

被験者さんから心理的に抵抗の大きい検査や献脳について、参加していただくことで何がわかるのか、科学的な重要性を説明。

2016 DIAD Family Conference

Too Young To Forget

Saturday, July 23rd, 8:00am-2:00pm ET

Fairmont Royal York Hotel (Ballroom) • Toronto, Ontario

Agenda Overview

- Family Presentations
- AD Research Updates (DIAN, DIAN-TU, field)
- Advocacy and Public Policy
- Panel Discussion
 - Advocacy and Pharma
 - Drug Re-purposing for AD
- Non-pharmacological & Pharmacological Approaches and Modifiable Risk Factors
- Caregiving and Long-Term Care
- Legal and Financial Matters
- Ethical Issues in Risk Disclosure
- Support Sessions

Welcome reception at the Omni King Edward Hotel, Friday, July 22nd, 7– 8 PM

家族性ADの家族会には、世界中から被験者・家族が集結。同じ悩みを抱える家族同士の交流会として非常に有意義。非常に熱狂的であった。



Knight ADRCの被験者さんとのコミュニケーション

- ◆ 3つの研究毎に年1回被験者ミーティングに招待
- ◆ 年2回研究成果を報告するニュースレターを送付
- ◆ その他にホリデーカードなど

CHARLES F. AND JOANNE KNIGHT
ALZHEIMER DISEASE RESEARCH CENTER (ADRC)

Knight ADRC and the Memory & Aging Project

HORIZONS

NEWSLETTER · VOLUME 21(2) · SUMMER / FALL 2016

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Get the Latest Knight ADRC News!

There are many ways to stay up to date on the latest news at the Knight ADRC.

“Like” us on Facebook: www.facebook.com/KnightADRC

Follow us on Twitter: @WUADRC

New information posted weekly on our website: <http://alzheimer.wustl.edu/>

Email phillips@wustl.edu to be added to our information e-distribution list.

Find the current list of Knight ADRC weekly seminars online at <http://alzheimer.wustl.edu/Education/Seminar.htm>

New Technique Clarifies Methods of Protein Clearance

New Alzheimer disease research details a technique that speedily measures in the brain of a damaging protein fragment, and insight into why mutations specific gene increase the risk of developing the disease.

The new measuring technique could lead to a better understanding of amyloid beta, a key protein associated with Alzheimer disease, is produced in the brain, which neuroscientists design treatments to reduce its accumulation.

When you use your brain – to remember the route to your neurons release a sticky protein known as amyloid beta, as a byproduct of their normal functioning. In healthy people, the protein fragment is cleared before it can do any damage. In people with Alzheimer disease, clearance is impaired and amyloid beta builds up into plaques.

Many of the treatments being tested for Alzheimer’s are designed to reduce amyloid beta in the brain. John Cirrito, an associate professor of neurology at Washington University School of Medicine, and his colleagues have developed a new technique that measures minute changes in amyloid beta levels in the brain. Previous techniques have required measurements only once an hour.

“For the last 14 years we had a technique in which we would do some mouse – give it a drug, have it perform a certain behavior – and we’d see what happened to its amyloid beta levels an hour later,” said Cirrito. “We found that wasn’t good enough. Neural activity happens on a rapid time scale, so we needed to see a direct connection between the intervention and the beta levels.”

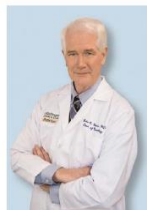
The researchers attached antibodies that specifically detect amyloid beta to a tiny electrode, zapped it with a small amount of voltage and measured the change in real time.

“People have used this approach for other molecules, but the detectors were too big, the size of a microscope slide,” Cirrito said. *continued*

(Photo: Robert Boston)

Update from the Director

All of our research volunteers are extremely valuable to the work of the Knight Alzheimer Disease Research Center. Building on a theme first discussed at our annual Participants’ Breakfast in June, I write now to emphasize the importance of each participant remaining fully active over time. It is only when we are able to detect change over time (such as in our clinical assessments, cognitive testing, imaging, and analysis of biofluids such as cerebrospinal fluid) that we can capture the initial occurrence of Alzheimer disease (AD). We want to detect AD when it first appears, as we believe that initiating therapies at that point, before there is substantial brain damage, holds the promise of delaying or even preventing Alzheimer dementia. Following healthy individuals over time also provides us with the opportunity to note what is “normal” as we age. Hence, I write to underscore the immense value of your participation in our studies over time.



I appreciate that we ask a great deal from you. I also appreciate that life brings conditions (such as an illness or death in the family) that unavoidably interfere with participating in our studies at a particular point in time. What I ask of you is to make all reasonable efforts when you are available to schedule and complete your assessments. In that way, we will move much closer to finally defeating this terrible disease.

With many thanks,
John C. Morris, MD, Friedman Distinguished Professor of Neurology

WU Students Win \$10,000 Award for AD Diagnostic Tool

Memento, an interdisciplinary team of Washington University students, won \$10,000 in a national competition for their mobile app designed to help diagnose Alzheimer disease more quickly.

The team is one of 10 finalists for the Student Technology Prize for Primary Healthcare, awarded by the Massachusetts General Hospital’s Ambulatory Practice of the Future and sponsored by the Gelfand Family Charitable Trust.

To receive a formal Alzheimer disease diagnosis, patients must be referred from their primary-care physicians to a neurologist. However, due to significant backlog, patients and their families may wait from several months to one year for an appointment, during which time a patient’s disease could rapidly progress.

To help shorten this process, the WashU team developed a mobile app to be completed by the patient’s caregiver to help a primary-care physician more accurately determine if a patient needs to be referred to a

neurologist for additional testing and diagnosis.

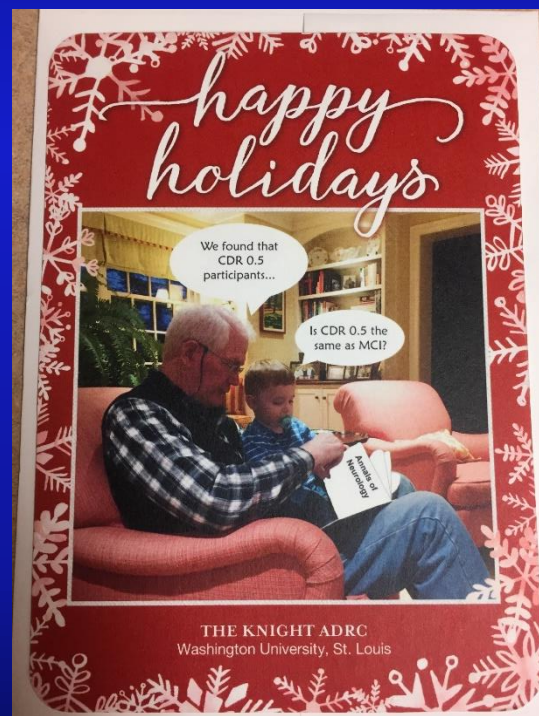
“The app replaces the 45 minutes of time spent by the physician interviewing the caregiver while simultaneously trying to scribble notes and answer the caregiver’s questions,” said Allen Osgood, co-lead of the team and a rising senior majoring in computer science in the School of Engineering & Applied Science. “By working through the app in advance, we give the physician, caregiver and patient more time to focus on the potential diagnosis and outcomes.”

In addition to the mobile app, Memento is developing an objective cognitive assessment. The team is working with neurologists in the Knight Alzheimer’s Disease Research Center, as well as the St. Louis chapter of the Alzheimer’s Association, on both aspects of its work and is preparing for a future clinical trial.



Co-leading the team with Osgood is Robert Chen, an MD/PhD student at the School of Medicine. Other team members include three additional Engineering students: Henry Morris and Matt Kramer, both majoring in biomedical engineering, and Rob Osorio, majoring in computer science. Mary Morgan Scott, a medical student; Hannah Bucklin, an MD/PhD student; and two May 2016 graduates: Dana Arcetti, who earned a bachelor’s degree in computer science, and Jenny Liu, who earned a bachelor’s degree in biology with a concentration in neuroscience.

By Beth Miller, first printed in Washington University Engineering News, August 2016.



Knight ADRCの地域社会への啓蒙活動

- ◆ Knight ADRCとしては、地域住民向けの認知症講座コース、地域の医師向けの教育プログラム、認知症患者と医学生をペアにしたプログラムを開催
- ◆ アルツハイマー協会支部主催の地域住民向けの講演会
- ◆ Knight ADRC, アルツハイマー協会, NIAが作成した様々な教育資料の配布



アルツハイマー協会

- ◆ 全米に支部があり、患者や家族のケアやサポートを含め、地域社会へのアウトリーチの中心的存在。
- ◆ 患者・家族、医療従事者を含め、様々なレベルの情報・教育を提供。
- ◆ 寄付の受け入れ窓口にもなっており、研究への助成も行う。

The screenshot shows the Alzheimer's Association website. At the top, there is a navigation bar with links for News, Events, Press, Contact, and Languages. The main header features the Alzheimer's Association logo and a search bar. Below the header, there are navigation tabs for About Us, eNewsletter, Message Boards, Action Center, Advocate, Walk to End Alzheimer's, Shop, and Donate. A helpline number (1.800.272.3900) and a chapter finder tool are also visible. The main content area is titled "Alzheimer's Association St. Louis Chapter" and features a "2016 IMPACT REPORT" section with the tagline "Alzheimer's is relentless. So are we." Below this, there are sections for "COMMUNITY RESOURCES" and "CAREGIVER CENTER". A news section titled "ST. LOUIS CHAPTER NEWS" includes a photo of three people and a headline: "Knight, Jaffe donate to Alzheimer's outreach". The St. Louis Chapter received \$750,000 to expand services.

The screenshot shows the website for the "WALK TO END ALZHEIMER'S" event. The header includes the event logo and navigation links for ABOUT, TEAMS, SEARCH, DONATE, REGISTER, and LOG IN. The main banner features a photo of a large crowd of people walking and the text "NATIONWIDE TOP 30 WALK". Below the banner, the event details are displayed: "2017 Walk to End Alzheimer's - St. Louis, MO" and "Take the first step to a world without Alzheimer's." The date "Saturday, September 16, 2017" is also shown. At the bottom, there are three buttons: REGISTER, VOLUNTEER, and DONATE.

WalkイベントはADの認知度の向上に役立っている。

日本の課題 —まず, 正しく「知る」場を作る

- ◆ AD, 認知症であることを隠したい患者・家族が多い.
- ◆ 研究の情報を正しく知る機会がなく, 研究参加に対して自分個人への利益を意図しがちである.
- ◆ 正しい知識を学び, 関心を持つことは, 患者・患者家族として病気と闘うため, さらに, 「共に病気と闘う」⇔「社会として病気を克服するために自分個人が何ができるか考える」ための第一歩.
- ◆ 一般大衆向けの教育の機会を増やしたい.

