

## Healthy Aging in Neighborhoods of Diversity across the Life Span

Winter 2005 Volume 1, Issue 3

## The Healthy Journey

handls.nih.gov 1-866-207-8363

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES • NATIONAL INSTITUTES OF HEALTH • NATIONAL INSTITUTE ON AGING

#### **HANDLS ACTIVITIES**

Over the past several months, the HANDLS staff has participated in several community events in Cherry Hill and Reservoir Hill.

#### Cherry Hill

On December 9, 2004, Ms. Paula McLellan hosted the Cherry Hill, Westport and Mt. Winan's Community Advisory Board meeting. We held the

meeting at the Family Health Center of Baltimore at 631 Cherry Hill Road. Even with the frightful weather, we had a great turn out. Cleoda Walker, Linda Towe, Addie Black, Julia Dinkins, Ruth Sherrill, Veronica Purcell, Margie Downs, and Paula McLellan attended the meeting. Thank you for coming to the meeting in the cold and rain. More members attended this meeting than any other **HANDLS Community Advisory** Board Meeting.

Intersection of Seamon Avenue and Seabury Road where we will park the Mobile Medical Research Vehicles on March 10.

The meeting agenda included our recently revised HANDLS video. The new film shows the mobile Medical Research Vehicles in Cherry Hill. After the

film, our Principal Investigators gave short talks. Dr. Michele Evans spoke on the background and purpose of the study. Dr. Alan Zonderman spoke about how HANDLS will look at memory and aging over the next twenty years. Our Study Nurse Practitioner, Pat Julien-Williams, and our Study Manager, Jennifer Norbeck, spoke about what participants will experience as members of the study.

They talked about the screening process at the doorstep, the home interview, and visit to the Mobile

> Research Vehicles. The presentations were followed by a question and answer period. Thank you so much for your thoughts on how to improve recruitment and where to park the Mobile Research Vehicles.

> We also thank Cherry Hill, Westport, and Mt. Winans Community Members who were unable to make the meeting on December 9. Thank you to Cathy Brown McCain of Cherry Hill 2000, Rosa McCoy of Cherry

Hill, Charlotte Bryant of the Ministerial Society of Baltimore, Jeff Topping, and Senator George Della of the Maryland State Senate. Your contacts and suggestions helped us plan our visit to your neighbor-

We will be at the intersection of Seamon Avenue March 10, 2005.



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hoods. We know you are very busy. Thank you for finding time to support this exciting project.

#### Reservoir Hill

On July 28, 2004, we held the first Reservoir Hill Community Advisory Board Meeting. Thanks to Darrell Smith from Reservoir Hill Mutual Homes, Inc. for allowing us to use their facility on Callow Street for the meeting. The meeting was well attended. We were joined by representatives from the Reservoir Hill Improvement Association, residents from the neighborhood, and members of the medical community. Thank you to Ms. Chartruse Robinson, Ms. Janet Downing, Dr. Rama Shankar, Dr. Nina Everett, and Ms. Denise Bailey Jones for attending the meeting. The study team is grateful for the opinions shared about the study design, the location of the vehicles, and the additional community contacts provided. We use the information from Community Advisory Boards when we plan to move the study to your neighborhood. If you would like to attend the next Reservoir Hill Community Advisory Board Meeting, please call Bridget Cromwell at 410-558-8404. She will make sure we notify you about the meeting schedule.

On October 9, 2004, we held an Open House at the Whitelock Street and Brookfield Avenue study location in the Reservoir Hill Community. This gave the Reservoir Hill community a chance to see one of the vehicles and ask questions about the study. In addition, Violet Sloat, a representative from the Commission on Aging and Retirement Education attended. She provided information about how seniors can get discounts on medications through a special program called the Access to Benefits Coalition, Ms. Sloat also shared additional community health and social service resources for seniors living in Baltimore City. Thanks to the Commission on Aging and Retirement Education for coming to this event and helping us to educate the community about these important resources. If you were unable to attend and you would like more information on the Access to Benefits Coalition project, please call the Commission on Aging and Retirement Education at 410-396-4932 or 410-396-2273. You can also visit their website at www.AcesstoBenefits.org.

On December 7, 2004, Dr. Michele Evans, one of the Principal Investigators, and Ms. Jennifer Norbeck, our Study Manager, attended the Reservoir Hill Improvement Association meeting to provide an update of the study to the community. At that time, the vehicles had been in Reservoir Hill for about a month. The response from the residents of Reservoir Hill was quite positive. We thank you so much for allowing us into your community and your homes. We greatly appreciate your continued support of the HANDLS study.

#### FOCUS ON HEALTH: ALZHEIMER'S DISEASE

Alzheimer's disease affects about 4 million people in the United States. Alzheimer's disease is the most common cause of dementia for people over age 65. Dementia is a general decrease in mental function. In this newsletter, we will discuss Alzheimer's disease, and we will describe the symptoms of the disease. We will give useful information to help you understand the disease process.

Alzheimer's disease is more common as people get older. However, not everyone gets this disease. It is

### Alzheimer's disease is more common as people get older.

not a normal part of aging. In Alzheimer's disease, there is damage to the nerve cells in all parts of the brain. The damage is permanent. Gradually, there is a decline in memory, thinking, decision-making, language, and the ability to control emotions and behaviors. In the end stage, people lose their abilities to remember and provide care for themselves. Based on the 2000 census, it is estimated that over 12,000 people in Baltimore City had Alzheimer's. People who have family members with Alzheimer's may have a higher risk for the disease.

#### How is Alzheimer's diagnosed?

There is no one test used to tell if a person has Alzheimer's. Memory testing is the most helpful.

Blood work, brain scans, and brain-wave tests are useful to exclude other diseases that have the same symptoms as Alzheimer's. Some of the other diseases with symptoms similar to Alzheimer's may be treated. Parkinson's disease, multiple small strokes, severe depression, thyroid disease, syphilis, vitamin B12 deficiency, and brain tumors must

# Alzheimer's disease is a permanent decline in memory, decision-making, and language abilities.

be ruled out before the diagnosis of Alzheimer's is reached.

#### What are some of the signs of Alzheimer's?

Alzheimer's disease has three stages that have different symptoms and behaviors: mild, moderate, and severe. For Stage I or mild Alzheimer's, the person has problems making sense of the world around them. It may be a long time before someone else notices that something is wrong. In this stage, early symptoms are often confused with changes that happen in ordinary aging. Symptoms of mild Alzheimer's may include:

- Difficulty remembering and changes in emotional speech
- Confusion about the location of well-known places
- Taking longer to complete normal, daily activities
- Trouble with easy math problems and tasks such as managing money, balancing a checkbook, or paying bills
- Bad judgment that results in harmful decisions
- Increased worry
- Changes in mood and personality

For Stage II or moderate Alzheimer's, the destructive changes happening in the brain get worse and spread to other areas. These parts of the brain control speech, intellect, logic, and attention. The fol-

lowing symptoms become more obvious and behavioral problems can begin:

- · Increased memory loss
- Decreased attention span
- Problems recognizing family and friends
- Difficulty with speech, understanding speech, reading, and writing
- Problems sorting out thoughts
- Failure to learn new things or deal well with surprising events
- Impatience, tension, anxiety, crying, and wandering, mainly in the early evening hours
- Repetitive comments or motions
- Hallucinations or delusions, mistrust or paranoia
- Lack of impulse control (for example, poor table manners, offensive language, undressing in improper places or at improper times)

For Stage III or severe Alzheimer's, all sense of self appears to fade away. Symptoms of severe Alzheimer's may include:

- Total loss of memory and language
- Major weight loss and loss of physical coordination
- Seizures, skin infections, and problems swallowing
- Crying out, complaining, or mumbling
- Increased sleeping
- Inadequate bladder and bowel control

#### **Treatment**

Right now there is no cure for Alzheimer's disease and we do not know what causes it. But if it is caught early enough there are medicines that may help slow it down. These medicines are called Aricept, Reminyl, Exelon, and Namenda.

## Is there anything I can do to reduce my chances of getting Alzheimer's?

Some of the same things that you do to keep your body healthy will help keep your brain healthy. Eat

more fruits and vegetables; eat less fried foods, like fried chicken, fried fish, or French fries. Cut down on salad dressings, mayonnaise and butter, or switch to the low fat type. Exercise at least a few times a week for half an hour, and more if you can – walk when you can instead of driving or taking the bus, especially when it is nice outside. If you have high blood pressure or diabetes, be sure to take your medications.

## Is there help for people who care for loved ones with Alzheimer's?

People who care for loved ones with Alzheimer's disease also need help. If you are caring for someone with Alzheimer's disease, there are groups that will help you find services. There are support groups that you can join to talk with others who are also caring for loved ones.

#### Tips for Caregivers

Although I cannot control the disease process, I need to remember I can control many aspects of how it affects my relative

I need to cultivate the gift of allowing others to help me, because caring for my relative is too big a job to be done by one person.

I need to take one day at a time rather than worry about what may or may not happen in the future.

I need to take care of myself so that I can continue doing the things that are most important.

I need to remember that my relative is not being difficult on purpose: rather that his or her behavior and emotions are distorted by the illness.

I need to focus on and enjoy what my relative can still do rather than constantly lament over what is gone.

I need to increasingly depend upon other relationships for love and support.

I need to frequently remind myself that I am doing the best that I can at this very moment.

I need to have a sense of humor because laughter helps to put things in a more positive perspective.

I need to structure my day because a consistent schedule makes life easier for me and my relative.

I need to draw upon the Higher Power, which I believe is available to me.

Source: The American Journal of Alzheimer's Care and Related Disorders & Research, Nov/Dec 1989

#### Tips for feeding persons with Alzheimer's disease

Getting someone with Alzheimer's disease to eat is a challenge and there is no one answer. The person caring for someone with Alzheimer's disease should try to encourage the person to eat. It is also helpful to keep mealtime less confusing.

- Provide a calm environment at mealtime. Limit noise and distractions. Turn off the television. Soft music can have a calming effect for some persons.
- Allow plenty of time for eating and make sure the person is sitting upright so food does not get suck in their throat.
- Avoid plates, tablecloths and placemats that have patterns. They might confuse and distract the person.
- Use bright colored plates like red or blue plates, rather than white plates to increase the amount of food the person eats. A strong contrast in color between the food and plate can also increase the amount of food the person eats.
- Have someone eat with the person so he or she can imitate eating. Some people with Alzheimer's do not know what to do with food or eating utensils. It helps them to eat with others and imitate their behaviors.
- You may need to put your hand over the person's hand to help them use forks and spoons.
- Check the person's mouth before and after eating to make sure that food is not stored in the cheeks of the face.
- Only serve one food at a time to avoid the person being confused by too many choices.

- Prompt the person to eat, chew, and swallow as necessary.
- Serve many small meals (6 meals) rather than 3 large meals.
- Serve finger foods- bite size food that can be eaten without a fork or spoon.
- Don't serve steaming or very hot foods or drinks.
   Always check food before serving to make sure it is not too hot.
- If the person is losing weight loss, serve healthy snacks like pieces of cheese or peanut butter on crackers.

#### If the person has problems swallowing,

- Blend the food or alternate small bites of food with a drink. For example, serve mashed potatoes rather than fried potatoes.
- If a person is having trouble swallowing, drinks may need to be thicker.

#### Examples of finger foods

- Hard-boiled egg or scrambled egg cut into bite-size pieces
- · French toast sticks
- Any bread or roll that can be picked up by hand
- Cold cereals that form large pieces and served without milk
- Any fresh fruit cut into bite size pieces or slices or eaten whole like small fresh berry
- Chicken strips, baked fish sticks, or meat patties cut into bite size pieces
- Oven brown potatoes, Tater tots
- Raw vegetables pieces like cucumber slices
- Cooked large slices of vegetables that have crisp tender texture
- Sandwiches cut into bite size pieces
- Ice cream cones and pudding served in ice cream cone

If the person is not getting enough to eat, meet with a Registered Dietitian to talk about how to increase their nutrition

#### Resources

Alzheimer's Association www.alz.org 1850 York Road, Suite D Timonium, MD 21093 1-800-272-3900

Alzheimer's Disease Education and Referral Center www.alzheimers.org P.O. Box 8057 Gaithersburg, MD 20898 1-800-438-4380

National Institute on Aging and Eldercare Locator www.eldercare.gov 1730 Rhode Island Avenue, NW Washington, D.C. 20036 1-800-677-1116

## UPDATE FOR LAURENS STREET PARTICIPANTS

Here is an update for people who participated in our Pilot Study on Laurens Street from October 2000 to June 2003.

#### What is happening with the MRV?

You may have seen our mobile Medical Research Vehicles in the Reservoir Hill neighborhood recently. Our study has changed since we left Laurens St. In November 2004, we started the main part of the study. In this part of the study, we will visit homes all over Baltimore to learn about people's health. We will be in the Reservoir Hill neighborhood until early March. Then we will move to Cherry Hill.

## How does HANDLS find participants for the main study?

You will notice that the way we find participants for the main study is different from how we found participants for the pilot study. You did not have to live in the neighborhood to participate in the pilot study. For the main study, we selected twelve Baltimore neighborhoods to visit. You must live in one of these neighborhoods to be selected. We select homes in each neighborhood by chance to get a sample that represents the people living in the whole neighborhood. If your home is selected you will receive a letter in the mail or a visit from one of our home interviewers. When an interviewer visits a selected home, they get permission to put information about the people living in the home into a computer. The computer program tells the interviewer who to select from each home to join the study. Sometimes the computer does not select anyone living in the home. If this happens the people in the home will be thanked for their interest in the study, but they will not be asked to join the study.

We cannot promise you that we will visit your household or that we will invite anyone in it to join. If you are selected to join, you will be able to see us before we come back for our next visit to Laurens St. We are not able to tell you in advance if your home has been chosen. However, if an interviewer comes to your home and nobody is there, they will leave a card telling you that your home was selected. They will come back in the next few days to talk with you about the study.

#### When will we return to Laurens Street?

We will be returning to Laurens St, but later than we planned. When we started, we thought the MRVs would return to Laurens St. to re-test the pilot participants in 2005. Unfortunately, because there was a delay in starting the main study we had to change the time line. That means we will return to the Laurens Street location a few years later than we planned. Keep an eye out in the HEALTHY JOURNEY newsletter for where we are and where we will be in the future.

## REMINDER TO ALL HANDLS PARTICIPANTS

Please make sure you let us know if you move so you can continue to stay connected with HANDLS through our mailings. You may contact Bridget Cromwell, our Community Outreach Coordinator, at 410-558-8404 to let her know your new address and she will update our records.

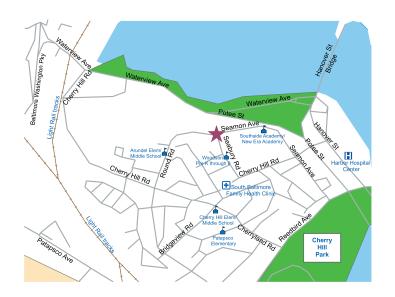
#### FOCUS ON THE HANDLS STAFF

#### Ngozi Ejiogu, MD

Dr. Ejiogu joined the HANDLS research team two years ago. She says, "Joining the HANDLS team has been exciting and challenging. I am originally from Nigeria, West African where I went to medical school. My residency training was at North General Hospital in New York City. I moved to Maryland and joined the HANDLS team. I am responsible for collecting the medical history, conducting physical exams, and reviewing clinical laboratory results. Like many urban areas in the United States, there are many health disparities in Baltimore City. The HANDLS study gives me the opportunity and privilege to be part of this groundbreaking research collecting important information that will be used to improve health care for all.



Ngozi Ejiogu, MD



#### Moving on!

Every three months we move the HANDLS Mobile Research Vehicles to a new location. We will move to the Cherry Hill neighborhood in South Baltimore in the beginning of March. We will park the Mobile Research Vehicles at the intersection of Seamon Avenue and Seabury Road. Our recruiters will visit homes in the Cherry Hill, Mt. Winans, and Westport neighborhoods.

The HANDLS mobile Medical Research Vehicles are located at the corner of Seamon Avenue and Seabury Road in Cherry Hill (on the #27, #29, and #51 bus lines).



#### HANDLS STUDY TEAM

**Back row (from L to R)** Michele Evans, MD (Principal Investigator); Ngozi Ejiogu, MD (Staff Clinician); Keith Staton (Logistics Manager); Patricia Julien-Williams, CRNP (Study Nurse); ToShun Campbell (Psychophysiology Tester); Angela Graham (Cognition Tester); Marcellus Merritt, PhD (Psychophysiology Research Fellow); Marc Mason (Statistician)

Middle Row (from L to R) Bridget Cromwell (Community Outreach Coordinator); Mary Lassiter (Ultrasonographer); Debbie Colby (Cognition Tester); Melissa Kitner-Triolo, PhD (Manager, Cognition Section); Virginia Padilla (Special Assistant to Dr. Evans); Clare Jefferson (Cardiovascular Technician); Kareem Brown (Software Engineer); Kamala Foster, MD (Study Clinician), Alan Zonderman, PhD (Principal Investigator)

Front Row (from L to R) Janet Donohue, MPH (Statistician); Elizabeth Burke (Cognition Tester); Shelley Allen (Medical Records Specialist); Jennifer Norbeck, LCSW/C (Study Manager); Jenny Lloyd (Neighborhood Survey Coordinator); Marie Fanneli-Kuczmarski, PhD (Nutritional Epidemiologist)

# The Quarterly Newsletter for the HANDLS Community Healthy Aging in Neighborhoods of Diversity across the Life Span

The purpose of this study is to learn about changes in health over time. Using our medical research vehicles, we want to study as many people with different backgrounds as we can. We want this study to help us understand healthy aging by examining the affects of different backgrounds on changes in health over time. The information that we gather will help improve health and prevent disabilities. We want to do this for people from all backgrounds, particularly those in poor and minority communities.

For information about our study call 1-866-207-8363 or visit our website handls.nih.gov



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