NWX-HHS-AOA-1

Moderator: Amy Wiatr-Rodriguez
June 13, 2012
12:15 pm CT

Coordinator:

Welcome and thank you for standing by. At this time all participants are in a listen-only mode. During the question-and-answer session please press star 1 on your touch-tone phone.

Today's conference is being recorded. If you have any objections you may disconnect at this time.

Now I would like to turn the call over to Mrs. Amy Wiatr-Rodriguez. Thank you ma'am, you may begin.

Amy Wiatr-Rodriguez: Right, thank you so much (Ashley). I'm Amy Wiatr-Rodriguez with the Administration on Aging which is within the Administration for Community Living, and I'll be moderating today's webinar, "Online Tools and Resources to Assist Individuals with Dementia and Their Caregivers: The National Alzheimer's Contact Center, Eldercare Locator and ADEAR which is Alzheimer's Disease Education and Referral Center, which is the second in a three part series. We just posted the slides and transcript from the first webinar to our AoA Web site and we will be sending an email to all who registered for

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT

Confirmation # 5228218

Page 2

that first webinar once the audio is posted which we hope will happen very

shortly.

This webinar series came about through discussions within AoA and our AoA

funded programs such as Alzheimer's Disease Supportive Service Program,

Older Americans Act Title III-E, National Family Caregivers Support

Program, National Alzheimer's Call Center and Eldercare Locator. And how

could we better collaborate with our colleagues at the National Institute on

Aging and their funded programs such as Alzheimer's Disease Research

Centers and the Alzheimer's Disease Education Referral or ADEAR Center?

We are so pleased that some of the participants in those discussions are

presenting today and others are featured on the other webinars in the series.

Before I introduce our speakers we have a few housekeeping announcements.

First, if you have not already done so, please use the link included in your

email confirmation to get onto WebEx so that you can not only follow along

with the slides as we go through them, but also ask your questions when you

have them through chat.

If you don't have access to the link we emailed you, you can also go to

www.webex.com, click on the Attend a Meeting button at the top of the page

and then enter the meeting number for today which is 669631314. If you have

any problems with getting into WebEx, please call WebEx technical support

at 1-866-569-3239. That's 1-866-569-3239.

As (Ashley) mentioned, all participants are in listen-only mode, however we

welcome your questions throughout the course of this webinar. There are two

ways that you can ask your questions. First is through the web using the chat

function in WebEx. You can enter your questions and we'll sort through them

> 06-13-12/12:15 pm CT Confirmation # 5228218

Page 3

and answer them as best we can when we take breaks for questions after each

presenter.

In addition, after the presenters wrap up we will offer you a chance to ask

your questions through the audio line. When that time comes the operator will

give you instructions as to how to queue up to ask your questions. If there are

any questions we can't answer during the course of this webinar we'll follow

up to be sure we get those questions answered. If you think of any questions

after the webinar you can also email them to us at amy.wiatr@aoa.hhs.gov or

you can email any of the addresses of the presenters that are included on the

PowerPoint slides that are the basis for this webinar.

As the operator mentioned we are recording this webinar. We will post the

recording, the slides and a transcript on the AoA Web site at www.aoa.gov as

soon as possible and hopefully by the end of next week.

Our speakers today include Karen Pocinki who is the Chief of the Health

Resources and Communications Group in the Office of Communications and

Public Liaison with the National Institute on Aging; Michelle Washko, PhD,

Office of Policy Analysis and Development with the Administration for

Community Living; David Parris, Senior Associate Director for the National

Alzheimer's Contact Center in the Alzheimer's Association; Mary Osborne,

Program Manager with Eldercare Locator at n4a; David Burton, the Project

Director of the Alzheimer's Disease Education and Referral or ADEAR

Center with the National Institute on Aging; and Jennifer Watson, Project

Officer with the ADEAR Center at the National Institute on Aging.

So we're very pleased to begin our webinar and at this point I'd like to turn it

over to Karen Pocinki, Karen?

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT Confirmation # 5228218 Page 4

Karen Pocinki:

Thank you Amy. Good afternoon to everybody and welcome to today's webinar. The National Institute on Aging is very excited to be participating with the Administration on Aging on this series of programs to provide federal updates on Alzheimer's disease care, research and resources.

As some of you may already know, NIA is 1 of 27 institutes and centers at the National Institutes of Health. We were established back in 1974 as the nation began to recognize that the population was indeed growing older and we needed to do something about that. We conduct and support research on aging which includes working with many of our sister institutes here at NIH on various diseases and conditions commonly associated with aging.

But the National Institute on Aging is the lead institute at NIH for Alzheimer's disease research. Along with research and the development of future scientists who study aging, we're also mandated by Congress to report research advances and to disseminate health information to the public and to health professionals.

And during today's webinar we're going to focus on a number of NIA resources including the Alzheimer's Disease Education and Referral Center or the ADEAR Center as we call it. Through its Web site and clearinghouse activities ADEAR is the federal government's primary source of information about Alzheimer's, about research to understand and treat the disease, about clinical trials and along with AoA about evidence-based approaches to care.

Jennifer Watson who is the ADEAR Project Officer and David Burton who runs the day to day operations of the Web site and the clearinghouse are looking forward to hosting a tour of these resources for you. We hope that you will take advantage of the information and the free materials available to both

06-13-12/12:15 pm CT Confirmation # 5228218

Page 5

patients and families and also to you as professionals in the field of aging and

care.

This is really a special time in Alzheimer's disease and research and care.

While we at NIA and AoA along with many of you have made significant

progress in what we've learned about caring for people with the disease and

understanding the disease itself, these efforts have received renewed attention

and support with designing of the National Alzheimer's Project Act back in

January of 2011.

In the year plus since we've stepped up our collaborations with AoA and other

federal agencies and have started to work more with the public and private

sector to help develop a national plan to address Alzheimer's disease which

was unveiled by Secretary Sebelius at the NIH Alzheimer's Disease Research

Summit last month. The research recommendations that came from the

summit which focused specifically on presenting and treating the disease are

now available on the NIA Web site at www.nia.nih.gov.

And I think Michelle is going to be telling you more about some of the other

activities under the plan including the establishment of a new portal Web site

to make it easier to access the resources that you'll hear about today. Again

we'd like to thank our friends and colleagues at AoA for organizing this

webinar series and we encourage you to listen and ask questions. And we

invite you to follow up with us at any time beyond the webinar series if you

have additional questions or anymore information.

And I also want to let you know that the upcoming webinar on July 12 is

going to feature information and insights about Alzheimer's disease clinical

trials and we look forward to that webinar series as well.

06-13-12/12:15 pm CT Confirmation # 5228218

Page 6

So thank you a lot and back to you.

Amy Wiatr-Rodriguez: Great, thank you so much Karen. And now I'm pleased to turn it

over to Michelle Washko, PhD.

Michelle Washko: Hi, thank you so much for having me today. Thank you to everyone who's

participating in this webinar of behalf of not just AoA, but the whole new

Administration for Community Living.

As you may or may not have heard the national plan to address Alzheimer's

disease set forth five goals including the development of effective prevention

and treatment approaches for Alzheimer's disease and related dementia by

2025. And in February of this past year the administration announced that it

would take immediate action to implement parts of the NAPA plan which

Karen mentioned including a public awareness campaign which has online

components.

There's a media campaign that's being launched and this campaign is really

targeted at reaching family members as well as individuals and patients in

need of more information on Alzheimer's disease. As part of this campaign

there are new television advertisements that are encouraging caregivers and

just Americans in general to seek information at www.alzheimers.gov.

Can we move to the next slide? Thank you.

This is a screenshot of alzheimers.gov which is a new Web site, HHS Web

site which will offer easier access to information and resources and support to

those facing Alzheimer's disease and their caregiving friends and family. And

it also gives a lot of simply basic information to the public about Alzheimer's.

> 06-13-12/12:15 pm CT Confirmation # 5228218

> > Page 7

And you can actually view these new television advertisements on this Web

site.

The site is a gateway to reliable and comprehensive information from federal,

state and private organizations on a range of topics including resources that

we will explore today in our webinar. Anyone who visits this site will find

plain language information which as anyone who works in government

knows, that's quite a feat. And tools to identify local resources that can help

with the challenges of daily living, emotional needs and the financial issues

related to dementia.

There's also video interviews of real family caregivers that explain why

information is key to successful caregiving, and it's in their own words. So for

all the partners who are working on this awareness campaign including all the

federal partners, we absolutely encourage you to check out this Web site.

I thank you all again for participating today, and I'll turn it back to Amy.

Amy Wiatr-Rodriguez: Great, thank you so much Michelle. And with that we're ready to

get into I guess the main topics of our webinar today. And we're going to

begin with David Parris with the Alzheimer's Association talking about the

National Alzheimer's Contact Center. David?

David Parris: Thank you so much Amy. It's a pleasure to be here. Very good. Okay the first

slide is exactly what our Web site presents. It is a world of resources at your

fingertips.

Amy, if you'll go ahead with the next slide please.

06-13-12/12:15 pm CT

Confirmation # 5228218 Page 8

What I want to look at are a couple of slides just briefly from this year's 2012

Facts and Figures. What you see in front of you - I mean one thing there's a

bar graph, but I think what's most important is that we take in the difference of

the experience of people who are actually caring for individuals with

dementia.

You will take note of the fact that the time that is actually spent doing various

activities with a person with dementia is that it's longer than is what is spent

with typically caring for an older person.

Next slide please.

And what I think is really important is that we take into consideration the

emotional toll as well as the stress that it takes in terms of caring over time for

a person with dementia. You will see the difference particularly in the

emotional stress of caregiving for people who are caring for people with

dementia.

And we take this in mind that it's a 24 hour helpline where I work and the fact

that we know that it's very important that when somebody calls us who's

looking for resources or emotional support that they connect immediately with

someone who gets - who understands what they're going through. I've found

that that is extremely important for caregivers, but it's also important for care

providers as well as persons who have been newly diagnosed with the disease.

Next slide please.

The slide you're looking at states our mission, the mission of the Alzheimer's

Association to eliminate Alzheimer's disease through the advancement of

> 06-13-12/12:15 pm CT Confirmation # 5228218

Page 9

research, to provide and enhance care and support for all affected. And to

reduce the risk of dementia through the promotion of brain health.

The things that I'm going to be mentioning today are those components of our

Web site in particular which address enhancing care and support, although

you'll see as I give you a brief overview that all aspects mentioned in the

mission statement are addressed on the Web site, and we have a very thorough

portal on research in itself.

Next slide please.

So some of the services that are available for caregivers I'm going to just

highlight here briefly and then we'll actually delve into them in the

presentation.

Not only is the national office in Chicago where the national 24/7, 365 or the

leap year 366 day a year helpline is available, we also have over 70 chapters

spread across the United States including in Hawaii as well as an affiliate in

Alaska where we provide hands-on services and programs as well as resources

for caregivers and persons newly diagnosed with the disease in addition to

ongoing trainings for people who are care providers throughout the

community.

I will be talking at length today about our robust Web site. I want to

emphasize that not only at the chapter level are there education programs, but

there are education programs that are embedded within our Web site that I

will be showing you links to later today. We also will be addressing safety

services, what to do in a crisis or disaster. And in addition one of the services

that we provide is family care consultation.

> 06-13-12/12:15 pm CT Confirmation # 5228218

Page 10

Now what this is can actually be individual care consultation or counseling

that will address not only emotional support for caregivers, but actually help

them figure out a care plan for their family and dealing with their particular

situation. This can be done either through our National Contact Center on a

24/7 basis or we can also set you up with individual meetings or also

teleconference meetings for family members through our chapter network. So

you could actually meet hands-on with somebody in your local community.

All of our 70 plus chapters offer support groups and these are not just in-

person support groups, but we also have telephone support groups that are

available for persons throughout the entire country. These support groups are

not just for caregivers. We have support groups that are very specific, ones for

individuals who have been diagnosed with younger onset Alzheimer's, for

people caring for persons with younger Alzheimer's disease.

We also have support groups specifically directed for kids and teens who are

affected by persons with Alzheimer's disease as well as for persons who have

been diagnosed with the disease at a more traditional age, 62 or after.

Next slide please. Next slide please.

Okay thank you. Oh go back one, I'm sorry. The next slide passed you too

fast. So we'll go to the one on the Contact Center right after that.

Okay very good, thank you.

Okay so what do we actually do at the National Contact Center? Well since

2003 we have served well over 2 million people just at our 800 number alone

and we owe this largely in part to a grant that we are provided by the United

States Administration on Aging. And we want to give a special shout out to

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT

Confirmation # 5228218

Page 11

our Project Director Amy Wiatr who's host for today's call, who has been extraordinarily supportive throughout the period that we've had this grant and

continue to have this grant.

We handle basically on average 3000 plus calls at the actual call center in addition to the 800 number itself; handles them throughout the chapter network. But the way that the 800 number works is that no matter where you're calling it from in the country a satellite dish is reading the area code on the number you're calling from and it's going to route to the nearest chapter of

where you are during business hours.

So if you're calling from let's say 212 in the New York City area, it will route first to the New York City chapter where you will provide - helpline service will be provided by the New York City chapter. If for some reason all their agents are busy or if it's a national holiday or after business hours, the call will automatically route to the 24 hour National Contact Center. So you will always be greeted by a live representative on the phone who will be able to assist you with not only local resources, but with emotional support.

Now the way we provide this is we have two sets of agents available. We have general information specialists who can answer questions about resources in the area. They can also answer questions about warning signs of the disease, how to get a proper diagnosis for Alzheimer's disease as well as provide directions often for support groups or special events that are taking place in the local area.

The other type of agent that we have are what we call our care consultants. These are all master's level clinical social workers. We have - or people with a master' level in clinical counseling or psychology. And in addition, though we do not have them dispersing medical advice, we also currently have three

06-13-12/12:15 pm CT Confirmation # 5228218

Page 12

nurses who serve as care consultants as well who have a counseling

background.

What we have found really interesting in the last few years is that we have

remained steady in terms of the amount of general information calls that we

receive and where as during the same time period we've had an extraordinary

growth of use of our Web site for information. But what has really increased

as well has been the need for care consultation. And what we have found just

in the past year, we had a 53% increase in care consultation calls. And thus far

this year we've had an increase of 26% over the previous year.

We ask ourself why that is? Part of it is because we're becoming better known

as an organization through word of mouth, through advertising, through links

through other Web sites such as some of those you will be seeing today. But

also what we have found is that people are reaching out for support when

they're in a time of crisis. So this is something we've had to address by often

having to involve Adult Protective Services.

We're also having to utilize first responders such as local police departments

and such because if we assess that there's an emergency situation taking place,

neglect, abuse and so forth, we want to make sure that we have hands-on eyes

on the situation that are able to do a second assessment of the situation and

that we're able to get these folks the assistance they need ASAP.

Next slide please.

So at the top what you're seeing is alz.org. This is our Web site, we're

extremely proud of it. It is an ever-growing, ever-changing Web site. It is just

tons of information. Now what we've got on here for you are three different

areas that are just small components of what's being presented. The map of the

06-13-12/12:15 pm CT

Confirmation # 5228218 Page 13

United States is a feature that's on the Web site is that under - you can click

Find Us Anywhere and you can click your state and it will bring up a link

directly to the Web site as well as contact information for the local chapter in

your area.

So there's a lot of different ways to find how to get into touch with your local

chapter or you can of course dial the 1-800 number. Below the map of the

United States and the Find Us Anywhere feature is a highlight on our

interactive brain tour. This is something that is extraordinarily popular with

people of all ages. The brain tour I want to note is offered in 14 different

languages. So it's a really great way to orient people of various backgrounds

into what actually happens with the brain and Alzheimer's disease.

The tour begins taking you through interactive slides that actually show you a

healthy brain and then what happens to the brain as it's impacted by

Alzheimer's and other types of dementia. And it'll take you through really the

entire process of the disease and how it affects the brain. So if you've never

seen this I would encourage you at some point to look at this. It's a very, very

illuminating tool.

And to the right of the slide you'll see an actual snapshot of our home page.

Our home page changes literally almost every ten days, so there are different

items that will be featured. There are some that remain constant, but I want to

show you the current shot of the Web page as it appears today. And that way I

can orient you with a few features a little bit closer.

If we can go to the next slide please.

Okay what you're seeing is the upper or the top fold if you will of our current

home page. I want to bring to the attention - let's start with the purple bar

> 06-13-12/12:15 pm CT Confirmation # 5228218

> > Page 14

that's about just almost a little over 1/3 of the way down. What you're going to

see are different drop-downs that will lead you to an enormous amount of

information in various areas. The first, In My Area will tell you what kind of

offerings are in your particular area and provide you the link to resources as

well as your local chapter within your area.

Then under Alzheimer's & Dementia the drop-down includes such things as a

discussion of myths about the disease. A link also to numerous and I'm talking

hundreds of publications that the Alzheimer's Association has made available

in PDF format or you can order them as brochures from the 800 number. So

all these things are downloadable from the Web site though and can be

printed.

Also under Alzheimer's & Dementia there is a thorough discussion of how to

get a diagnosis for the disease, questions to ask when at your doctor as well as

a discussion of the ten warning signs. Third over, Life with Alzheimer's

disease. This is one of the ways you can connect to our message boards or

ALZConnected which I'll speak about a little later in length.

There's a specific section in there of if you have the disease and it discusses

about planning ahead and also just tips and suggestions how to live with

Alzheimer's disease to help the individual who's newly diagnosed. There's

also a thorough discussion about living with younger onset Alzheimer's

disease. A discussion about financial matters how to qualify for social security

disability and then we also have which I'll talk about a little more in length

later a very special section just for kids and teenagers.

We also feature in this same drop-down information focused directly for the

African American community and then that for the Latino community as well.

> 06-13-12/12:15 pm CT Confirmation # 5228218

Page 15

Under Professionals there are information specifically directed for physicians

and also for professional care providers including the essentiALZ which is an

online course on dementia care which talks about person-centered care and

really is a comprehensive online course with certification that allows

individuals who are just interested in caring for a person with Alzheimer's

disease, who know someone who is caring for someone with Alzheimer's

disease or for CNA's and other professionals who want to get some basic on-

hands training.

There is an initial four hour course and there's an additional ten hour, both

which have certification. And finally under the We Can Help just one more

over, the drop-down includes things such as a link to the 24 hour helpline, to

support groups, to our Safety Center which I'll speak to in a few minutes as

well as our Senior Housing Finder. The Senior Housing Finder is a service

that allows you to do an individualized search for care facilities throughout

your community or for a neighboring community.

Or if you're a long distance care provider, you can put in the zip code and do a

search across the country for an area where you may be looking for a care

facility for someone in the future. The other thing that's here that I'll speak to

later under We Can Help is our virtual library which you can have access to

on a 24/7 basis as well.

Next slide - oh no let's stay with this.

One other thing that I wanted to show you. At the very, very top right corner

you will see where it says the word Language in a box with a little arrow to

click down. Here you have an option of going onto language portals in 14

different languages. The most robust, there is a complete - essentially

> 06-13-12/12:15 pm CT Confirmation # 5228218

10n # 5228218 Page 16

comparable Web site in Spanish as well as an Asian portal that features

materials both in Vietnamese, Chinese as well as Japanese.

We don't have as robust resources in the other ten languages that are listed,

however they are being worked on even as we speak. So that we hope by this

time next year all of them will be equally robust to the English Web site.

Okay if you want to go ahead to the next slide please.

What you're seeing here are two of the other portals on caregiver resources

that I had just mentioned. One is the Spanish portal which has basically is a

mere reflection of the English Web site, so you can use the map as you can

see at the bottom corner the Spanish home page to find local resources in your

area. There also is access to all our brochures and PDF's in Spanish as well.

Similarly we have our Chinese portal which is featured in the lower left corner

there.

Next slide please.

So I mentioned the message boards. What this is in particular, these are

housed in a new section that we launched back in February called

ALZConnected and what we're featuring here is actually a social media

community that allows caregivers and other persons interested in Alzheimer's

disease and care to talk with each other. And how they can do this, it's easy to

join. They can do this in various ways.

They can with someone's permission actually speak with another caregiver

who has a similar profile to theirs in terms of perhaps also caring for someone

with younger onset disease and early stages or they can actually join specific

> 06-13-12/12:15 pm CT Confirmation # 5228218

Page 17

groups that have been established in ALZConnected that have various topics

that are being discussed.

In addition the message boards which were a popular feature on our Web site

prior to the launch of ALZConnected have been continued and what the

message boards provide are a number of forums where individuals can get in

and read about various caregiving situations or challenges that others have

faced and they can read the actual answers that have been provided not only

by care professionals, but others who are providing hands-on care to persons

with Alzheimer's and other dementias.

One of the other features on here that exists is that you're able to actually do a

search by topics. So if you're interested for instance in incontinence, you can

type in the word and up will come a number of posts that have previously

discussed with topics. So this is a great source for information.

Next slide please.

Another feature that I'm just going to speak very briefly on is Trial Match.

This is a comprehensive search tool that allows an individual to look for

dementia specific clinical trials in their area or an area that they or a loved one

might have access to participate in a clinical trial. There are a couple ways to

participate in this particular program Trial Match. One is to create a profile on

the Web site, on Trial Match page or one can use the 800 number and call in

between 7:00 and 7:00 Monday through Friday and we can help you

individually to establish a profile.

We're actually going to be presenting on Trial Match on the July 12 call, so I'll

let my colleague Martha Tierney speak to that more in July.

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT

Confirmation # 5228218

Page 18

Next slide please.

There are a number of educational opportunities and online tools for E-learning that are available on the Web site. Currently we have one that's called The Basics of Alzheimer's Disease and Memory Loss and this is featured in both English and Spanish. It runs about an hour, these are interactive videos with caregivers as well as researchers talking about the basic components of the disease as well as the importance of getting an early diagnosis.

Other courses that are available in an E-learning format online include Knowing the 10 Warning Signs in both English and Spanish as well as legal matters and planning ahead. And I'm pleased to say that within the new month we are going to be launching Living with Alzheimer's for Caregivers in the Early Stage, Middle Stage and Late Stages. So these will be three part series as well as Living with Alzheimer's for people with Alzheimer's disease themselves in a three part series.

And finally there will be a separate one launch specifically for living with Alzheimer's for younger onset diagnosis.

I want to call attention to the second page and that is our virtual library. This is a marvelous feature that is available. It gives you access to our Green-Field Research Library which is the nation's largest library and resource center specifically devoted to increasing knowledge about clinical, scientific and social aspects of Alzheimer's and related dementia.

Available here is an opportunity to answer questions about Alzheimer's disease and related dementia. Search for materials and topics, locate statistics, find a certain article or book title or actually get connected with resources. So I would encourage you to explore this tool as well.

06-13-12/12:15 pm CT

Confirmation # 5228218 Page 19

And finally this was launched about a year ago, our Kids & Teens portal.

These are interactive videos and games that are on our Web site that orient a

teenager with the disease and actually speak to their experience as well as

persons who are under 12 who are dealing with caring for or living with

someone with Alzheimer's disease.

Next slide please.

I am really proud of the Caregivers Center. Our Caregivers Center was

launched last week. And what you will find here is a comprehensive web page

that speaks to every conceivable aspect I believe of the caregiving experience.

I'm going to just highlight a few features. You can see that you can - there are

connections to the message boards, but also on the far right there's also a care

team calendar. This used to be called Lots of Helping Hands.

But it's a way for families and friends to actually in a secure system arrange to

have people help out in certain ways. For instance take a person with dementia

on car rides or on doctor's appointments or to provide in-home care to give

respite for a caregiver and so forth. There's also a caregiver stress check that

one can take to monitor where they are in terms of their caregiving health.

Also there are features which will link you to explanations as well as referrals

for things such as adult daycare centers in your area, in-home care. There are

thorough discussions on standards of best care as well as coordinating services

and learning how to best work with care providers and working with your

doctor.

Next slide please.

> 06-13-12/12:15 pm CT Confirmation # 5228218

> > Page 20

Also included in the Caregivers Center is the Safety Center. Now this is a vital

part of anyone's life who's providing care for a person with dementia. The

Safety Center is extremely comprehensive and it addresses many, many

aspects if not all of caring, best practices for safety and caring for a person

with the disease. There are tips if you look to the far bottom right under

special situations, there's a discussion of traveling with a person with the

disease and how one plans ahead best for that.

And suggestions for instance time of day that's best to travel. Notifying for

security ahead of time for going through the security and so forth. And then I

want to call your attention to a specific area where we address how to deal

with situations deemed a disaster. I think everyone knows that when

Hurricane Katrina and Hurricane Rita came around it didn't just impact the

families in the area and their homes, it also impacted persons with dementia

who had to be relocated, nursing facilities and hospitals that had to relocate

patients.

So there's a thorough discussion in here of the importance of families planning

ahead in terms of prescriptions, in terms of emergency contacts, prevention of

wandering, in terms of educating people about a natural disaster when the

President has declared an area a natural disaster area. The changes in

Medicare protocol and accessibility for medical services. So I really would

urge you to check this section out.

Next slide please.

Amy Wiatr-Rodriguez: Hey David, this is Amy. We're getting right to the end of the time,

so if you could try to move through the next couple of slides quickly. I know

you're almost done anyway.

06-13-12/12:15 pm CT Confirmation # 5228218

Page 21

David Parris:

Absolutely. Safety services, here's a page for some actual products, medical

alerts, safe return and Comfort Zone, a comprehensive GPS tracking system.

These are two services available to assist with wandering prevention.

Next slide please.

And then I don't know where the pictures are, but Dementia and Driving

portal that is part of the Safety Center is an excellent way to address a very

difficult discussion that folks wind up having with persons with dementia at

some point. And that is assessing driving safety.

I would encourage you to check out - there are actually for different video

scenarios that are enactments based on real situations that came not only

through our support groups, but also through the 24 hour call center that deals

specifically with how to have a conversation with people in various points of

the need to address driving privilege.

Final slide please.

And finally I can't urge you enough, please feel free to utilize our 800 number.

We are here 24 hours, seven days a week. Every major holiday - all holidays.

And the Web site which is listed below. And should you have further

questions of me if I can be of any assistance my email is listed there for you.

I want to thank you for your time and Amy thank you for the prompts about

time. Okay.

Amy Wiatr-Rodriguez: No problem, we have so much information to discuss. I'm sure any

of our individual Web sites that we talk about we can take a full hour and a

half if not more. So thank you David. We did have a couple of questions that

06-13-12/12:15 pm CT Confirmation # 5228218

Page 22

came in through the web chat, so let's turn to that and ask you about those real

quickly.

The first question was from (Patsy) and she asked if you have any resources

that exist for families of individuals with Pick's disease?

David Parrish:

We have some. They are more likely than not, not Pick's specific, although this varies chapter to chapter. There is actually a Pick's Helpline I believe and sometimes we will refer people to that organization as well, but often our local chapters will have referrals for resources that can address Pick's disease.

And we realize sometimes people have a dual diagnosis as well. I hope that answers your question. Probably not as specifically as you would've liked.

Amy Wiatr-Rodriguez: Okay and if not maybe we can get that answered later when we open the audio lines. We have one more question and this may have come in before you got to that portion, but I think it's good information to review as well.

Question from (Jisun) came through. Does the Contact Center have language assistance for limited English speaking families and elderly persons?

David Parrish:

That is a terrific question and something I neglected to mention. Yes indeed, we have both a line for hearing impaired and deaf individuals to utilize as well as we have access 24 hours, seven days a week to a language line where we have access to 176 languages where we can get an interpreter within a matter of five minutes or less online who can provide interpretation. And we can provide resources and care consultation through the use of the interpreter.

06-13-12/12:15 pm CT Confirmation # 5228218

Page 23

Finally I would want to emphasize that we do have a number of bilingual agents. One who speaks Korean and about eight who are bilingual English/Spanish who when they are available on our phone line it will give you a prompt to speak to a Spanish speaking agent if so selected.

Amy Wiatr-Rodriguez:

All right.

David Parrish:

I don't know if that answers the question.

Amy Wiatr-Rodriguez: Yes and again if any other clarification is needed, if people could save those questions until we get to the audio portion or for people that do have additional questions, please you can submit those via the web chat right now. But we'll be waiting and opening the audio lines at the end of all of the presenters.

So with that we'll move right along. Thank you David and we'll move right along to Mary Osborne who is with the Eldercare Locator. Mary?

Mary Osborne:

Thank you Amy and hello everyone. Good afternoon. I'm so happy to be able to talk to you today about the Eldercare Locator. I welcome the opportunity and hopefully they'll be some new information available as I talk today for you.

Looking at this slide you see that I put on there the new Eldercare Locator and as everyone knows it's not really new. It's been around a long time. We always call it, it's the first step to making that connection to local resources. But what is new about it is in the last couple years we have really improved the technology of the program. It's much more sophisticated as well as enhanced the actual services that are being provided.

06-13-12/12:15 pm CT Confirmation # 5228218

Page 24

So we are keeping attuned to what's going on and keeping, you know, up to

date to provide the best service.

Next slide.

For those that are not familiar with the Eldercare Locator or at least not

familiar with this portion of it, I always like to start with the history of it. The

Eldercare Locator is a free public service of the Administration on Aging. It is

their program. We have been fortunate here at n4a to have been able to

administer this program for the Administration on Aging for about 20 years

now.

So you can imagine in that time frame how the program has changed over the

years and it's a very exciting, essential program to connecting people to local

resources. There are two primary components to the program and that is our

call center which most people are familiar with as well as the Web site. And

the call center has been around since 1992, that's really when it went national.

And well today I'm going to be talking mostly about the Web site. I wanted to

start and give you a little bit of information about the call center and some of

the new components to that.

The call center is open from 9:00 am to 8:00 pm Eastern Standard Time. We

do have live agents taking calls. There are also - we have like an after hours

service that is available so that in any time you call the Eldercare Locator

you're able to get the information about your local resources. If you call

within the hours of operation of the call center you're actually going to speak

to someone. Otherwise after hours you are put into like a self-service type of

system that actually can provide you what is in the database regarding your

local agencies.

06-13-12/12:15 pm CT Confirmation # 5228218

Page 25

We have bilingual staff and a language line service that we are able to provide

assistance with over 150 different languages as well as we do online chats

now and lots of emails coming into the call center. Last year we did almost

200,000 calls came in and what is always interesting to me is that most are

first time callers. They are not aware of the services available in their

community. Many of them have just found themselves in a situation where

they need help and they don't know where to start, so they call us.

We have two levels of staff that are taking calls. We have the information

specialist that is taking the inbound call and triaging the call. They're trying to

identify, you know, the core issue or service that that caller needs. It is person-

centered service, so we are always being guided by what is most important to

that caller and what they are looking for for this particular call because many

as you know are in very difficult, complex situations.

For those callers that may have dementia or be a little confused or may need

more help on a topic or item that they're looking for, we also have a second

level staff and these are master level staff that actually take more time with

that caller and can really hone in on other issues regarding what the, you

know, the caller situation and what they may need.

Both staff offer additional resources as well as connect that caller to the local.

We actually can stay on the line with the caller and introduce them to the staff

that answers the phone at the local level and sometimes, you know, explain

the situation for them. So the - to begin regarding the Web site which I am

going to focus on. The primary service of that Web site is the searchable

database and this is where we are identifying all your local agencies and

providers.

06-13-12/12:15 pm CT

Confirmation # 5228218 Page 26

These are - because it is a government Web site, these are considered your

most trustworthy resources. They - we also have on the Web site lots of

information about topics. We have various tools for caregivers and

professionals and we look at this as the first step to actually accessing needed

services.

Next slide.

This is a screenshot of the Web site eldercare.gov and you see along the top

bar the phone number. That is our call center phone number. I've also

highlighted in these three areas on the web page of what I'm going to talk a

little bit more about. As I said the primary feature of this Web site is the

searchable database and it does contain all the listings of those 629 AAA's.

We have the Title VI programs included as well as recently we've also added

all the ADRC information also.

You'll see that you can search by your location putting in your zip code, your

city/state. You can also search by topic if you're wanting to know just a little

bit more about a topic as well as I've also featured there on the right-hand side

of the page our online chat. And this feature has been growing in popularity.

Many times as someone goes through the Web site, if they have a question,

this is an opportunity for them to just go ahead and ask that question.

And then we do also have many of the visitors to the Web site actually calling

us then.

Next slide.

So to begin when we're talking about searching on the Web site, to search by

location, as I said this is primarily what visitors use. It is also - the Web site is

06-13-12/12:15 pm CT Confirmation # 5228218

Page 27

like a component that we work with here also in the call center. Our staff are

going on this Web site actually to identify the listings and we include all the

local aging network agencies as well as any other service providers that they

have put on their site to be able to help us connect that caller to the

appropriate resource.

So some of these other service providers might be the legal services, it might

be elder abuse. It might be ombudsman. It might be SHIP, you know, a

number of the other programs. The information is maintained and kept

updated at all times, so it is the most accurate. It is standardized in the listing

so every page will have the information - the information is listed in the same

order. It will have, you know, under each listing it will have all the different

information. So it's all standardized.

As well as we have now begun adding lots of description of the services and

special notes on each of the pages.

Next slide.

This is a sample of a page that I've pulled up to just show you that once you

search by location this is what you're going to find. And as you see there, you

know, we have the name of the agency. We have the address, the city, the

state. If they have a Web site, the office phone as well as any toll-free

numbers will go on here. Language - primary languages that they're able to

serve as well the description. Special notes, hours. There's a link to look at if

you want to actually visit this agency where you can click on it and see the

map of where they're located.

I've also highlighted a couple other links. One is if again if you think in terms

of the individuals that are coming to this Web site, many of them don't know

NWX-HHS-AOA-1

Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT

Confirmation # 5228218 Page 28

what services really are. And so here on the left side of the page I'm showing

where if you click on the little question mark it's going to bring you up

information that tells you a little bit more about what our information in the

system services for example.

And it just, it gives them the little definition, guides them, is this the best place

for me to contact. Also on the right-hand side of the page there they have

coverage area and many of the agencies have this available where they

actually show the zip codes that that agency serves. If the zip code isn't listed

there, then you scroll down and you can check the other coverage areas and

you might find there is another agency that's closer to you that, you know, if

you want to actually visit them that it would help you in determining which

one is the appropriate one for you to seek services at.

Next slide.

If you are wanting to say, look up a topic before you begin your search, I've

linked on the caregiver topic on our Web site just as an example for you to see

the type of information that you will find if you link on that. And here begin

with some resources. On this particular page one of our national resources of

course is the Alzheimer's Caregiver Center that David just talked to you about.

So as you see David mentioned this was just kind of a new thing that came up.

Our site is automatically updated to be the most accurate, the most current, the

most appropriate resource. It gives in this particular topic it's going to give

you information regarding the family caregiver support program which is one

of the Older Americans Act programs. It talks about what it is in the services

under it.

06-13-12/12:15 pm CT

Confirmation # 5228218 Page 29

Also there to the left of the page is one of the fact sheets that are available on

the Web site. And this again looking at caregivers or professionals that are

helping individuals with dementia. This is a good tip sheet. And one of our

more popular as to how to provide more assistance to agitated passengers

trying to transport them to doctors or various appointments that they may

need. It's very helpful.

Next slide.

And I just wanted to add here lots of other online tools and resources

available. We do have a caregivers corner and that is accessed from our home

page. Lots of other resources that there is also kind of a section in there that

talks about tips for caregivers. You can also add tips if, you know, you might

have one that you found is very helpful to caregivers. We also have a link

there providing news and information and this information is generally from

many of our partners.

The Eldercare Locator is part of a federal partners group which includes

agencies such as CMS or Social Security or Veterans and a lot of times we

have little links on that news and information section on things that might be

helpful for not only consumers, but also professionals to know more about.

Say Medicare news or the new information coming out with the veterans and

the veterans call center.

It also has lots of national Web sites and other links for professional, you

know, agencies - partner agencies. We have - widgets are available. You

could put up one of the little widgets, it's a little search feature on your Web

site and you can then - actually people visiting your Web site can also put

information in there and find other local resources.

derator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT

> Confirmation # 5228218 Page 30

As well as this is a wonderful tool for, you know, long distance caregivers that

are visiting, you know, their local agency site or looking to find services and

resources in the community and where their loved one is. It also has - we have

drop-in articles which these are free for anyone producing newsletters that

wants to, you know, looking for information on that to go ahead and just cut

and paste this. It's free. You know, you can fit it wherever you want. It's just

there for your use.

We also have a mobile version of the Web site now. And lastly we have the

Eldercare Locator Resource Center which is very popular. This is where you

can order brochures, you can download or order them online. There's fact

sheets that are printable.

Next slide.

And these are just some of the brochures that are on the Resource Center. We

find that these brochures are very, very popular with all our partner agencies.

They're ordered in large bulk for use at different events and we just welcome -

they're free. For large orders we do usually just ask that you pay for the

shipping.

I have a sample on here our newest brochure which is the Hospital to Home

brochure and this is one that was developed for all the care transition projects

and initiatives that are going on. And it's been so popular. It was launched in

December and we have distributed almost 5000 copies of that brochure. Many

of the agencies are using it, putting like their own little local information on a

sticker on the front and we just - I mean this is great for us and we welcome

your use of it.

06-13-12/12:15 pm CT

Confirmation # 5228218 Page 31

It can be - the Resource Center can be accessed both through the eldercare.gov

Web site as well as from the n4a Web site.

And let's see - next slide.

I think that's - oh one more thing. Social media. This is a great tool for

professionals. I mean lots of things are posted on this each day. These are

links to research, what's going on, different events going on. Just all kinds of

things that might be helpful for you wanting to keep up with all the aging

news and, you know, seeing what others are talking about and doing. So I

encourage - if you're not a friend please join us.

I think that's the end of my presentation. This is my information and feel free

to contact me. Thank you for the opportunity to come and talk to you and, you

know, like I said if you have any questions feel free to contact me.

Thank you.

Amy Wiatr-Rodriguez: Wonderful, thank you so much Mary. And we do have a couple

questions that have come through the web chat and we can try to get those

quickly before we move onto ADEAR Center.

So the first question is if Eldercare Locator staff are trained to identify callers

with Alzheimer's disease or other dementia?

Mary Osborne:

They are. We do have very in depth, ongoing training of staff for all types of

callers, but we do know that many of our callers are confused and may be

suffering early stages of dementia. So they are trained to be able to recognize

that caller as well as then they're going to know to either transfer it to a

counselor or that it is going to require a warm transfer.

06-13-12/12:15 pm CT Confirmation # 5228218

Page 32

And so they will stay on the line with that caller and kind of hand them off.

And they'll provide assistance with kind of relaying basic information to that

next agency staff that is answering the call. So yes.

Amy Wiatr-Rodriguez: Great, thank you. And then another question and I'm not sure if

this is for you specifically or maybe David or maybe even if Jennifer and

David Burton might be covering this and what they're going to - and I'll be

talking about next.

But we have a question from (Lisa) regarding statistics of the number of adult

children caring for an older adult with dementia. Do any of our panelists have

any information on that?

David Parris:

This is - go ahead.

Amy Wiatr-Rodriguez:

Go ahead David.

David Parris:

Well I was just going to say I can't give you the actual statistic right off the

top of my head, but the caregiver slides that I showed at the very beginning of

my presentation were from the 2012 Alzheimer's Association Alzheimer's

Disease Facts and Figures. You can access that on our Web site, so if you go

to alz.org and just do a search Facts and Figures 2012 you'll link directly to it

and that information is in that publication.

Amy Wiatr-Rodriguez: All right, great. And as I've mentioned before we will be posting

the slides and other materials from this webinar to our AoA Web site, so you'll

be able to get those slides that David referenced once we post them.

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT Confirmation # 5228218

Page 33

And then one more question before we move onto ADEAR and this came from (Carole) and I'm not sure if I'm understanding the question entirely, but she was wondering how people learn about the resource - I'm assuming Eldercare Locator. I know that question may have come in before you talked about your Facebook page and other things, but maybe do you have any other stuff that you do Mary or that you can talk about in terms of your outreach and public awareness activities on Eldercare Locator?

Mary Osborne:

We do. We do a lot of outreach, a lot of marketing. Like I said most of our callers are first time callers so this is a cue to us that lots of people out there don't know about us. We do a lot of national campaigns keying in with different media groups to get the word out. We do spot advertising in various markets.

We also do a lot of conferences, a lot of meetings, you know, that we participate in to present. We also are part of a federal partners group which our information is on all like letters that go out from Social Security or Medicare, Veterans. Along the bottom of their letters are always for more information or more resources please contact the Eldercare Locator.

So we are always also looking for new markets in new areas and welcome any ideas or suggestions.

Amy Wiatr-Rodriguez: All right, wonderful. Well thank you so much Mary. And we've got more information to come, so without any further adieu I want to turn the presentation over to David Burton and Jennifer Watson who are with the Alzheimer's Disease Education and Referral or ADEAR Center.

David and Jennifer?

> 06-13-12/12:15 pm CT Confirmation # 5228218

> > Page 34

David Burton:

Thanks Amy and hi everyone. Because there may be general interest on the part of the Aging Network participating in today's webinar we wanted to start first with the overall NIA Web site and then we will show our Alzheimer's channel.

The NIA sites were totally redesigned late last year. The new site is much more contemporary and cleanly organized to making the information much easier to find and search. Starting with the home page which you see here, you will see prominently displayed at left a slide show which gives us the capability of calling attention to events such as this slide pointing to the recent Alzheimer's Research Summit and the recommendations that emerged from the meeting.

The new design helps to illustrate that the NIA is a biomedical research agency and offers a wide array of evidence-based consumer health information. Please note that above each of these screenshots you will see the web address for that page in case you want to jot the address down and visit that page later.

Next slide please.

So we're still on the home page here. You can see that the What's New section at the top right features aging and Alzheimer's disease news, announcements and research highlights and below that there are three tabs providing quick links to resources by audience or the public which provides a variety of information related to health and aging.

Or researchers, which offers information on grants and training opportunities, research tools and other scientific research resources. And for healthcare providers providing publications for patients, information about clinical trials

> 06-13-12/12:15 pm CT Confirmation # 5228218

> > Page 35

and training materials. Across the top you will see a series of buttons with

pull-down menus including our Health and Aging channel which is our

primary destination for consumer health information.

Next slide please.

So when you click on the Health and Aging button where you can view our

featured health topics including caregiving, memory, planning, exercise,

healthy aging and more. In addition this page provides access to our A to Z

Health Topics Index, our Health and Aging Organizations Directory, E-Alert

subscription sign ups, links providing information about participating in

clinical trials, news of note and our Health and Aging FAQ's.

Next slide please.

By selecting one of the featured health topics such as Memory/Cognitive

Health you will see a page with a brief description of the topic, then a series of

related NIA publications, news, related research and links.

Next slide please.

On the Health and Aging channel when you click on Publications the NIA's

entire catalog of publications will come up in alphabetical order. All NIA

publications are available online to read and download and all are in the

public domain meaning that you can copy and edit or customize them as

needed. All of our print materials are free and shipped to you for free and bulk

copies are available for organizations.

Next slide please.

06-13-12/12:15 pm CT

Confirmation # 5228218 Page 36

Among the other options in the Health and Aging channel you can select our

Health and Aging Organizations Directory. This started life many years ago as

a collaborative effort with the AoA as a print publication called the Resource

Directory for Older People. Since then it has been converted to this online

database listing more than 350 organizations. It is searchable by name, key

word and category or topic area.

Next slide please.

Here we are back to the home page, and I just wanted to point to the top most

navigation on the right side of the page providing easy access from every page

in the site to NIA's family of health information sites including Alzheimer's,

Go 4 Life, Espanol and NIHSeniorHealth.

Next slide please.

Here's the landing page for the NIA's national campaign to promote exercise

and physical activity among older adults called Go 4 Life. This interactive

Web site features a wealth of evidence-based consumer-friendly information

about exercising, forming an exercise plan and sticking with it. Planning and

tracking tools for your exercise activity and many resources for older adults,

family members and professionals.

Next slide please.

The NIA Spanish channel provides health and aging information in Spanish

for seniors and family members including Alzheimer's disease. Our full list of

Spanish health topics in the same A to Z Health Topics list like the English

versions free publications which you can view and print or order in bulk.

Forty-four Spanish fact sheets from the Food and Drug Administration which

06-13-12/12:15 pm CT Confirmation # 5228218

Page 37

are available to order and links to agencies and organizations offering

resources to the Spanish speaking population.

Next slide please.

This slide shows nihseniorhealth gov which is a collaboration between the

NIA and the National Library of Medicine and was also recently redesigned.

The site was built especially for older people where you can easily resize the

text and change contrasts. NIHSeniorHealth provides nearly 60 topics from

NIH including Alzheimer's and caregiving, exercise stories, health videos,

training tools and email updates.

And now I'm going to turn it over to Jennifer Watson, my colleague who is

the Project Officer for NIA information clearinghouses at the NIA's Office of

Communications and Public Liaison.

Jennifer Watson: Thanks Dave. Hi everyone, I'm glad to be with you today and batting cleanup

to introduce or maybe reintroduce you to what may be a new resource. And

that is our ADEAR Center Web site.

As Karen mentioned way back in the introduction the National Institute on

Aging is the lead federal agency for Alzheimer's disease research and

Congress created the Alzheimer's Disease Education and Referral or ADEAR

Center in 1990 at NIH to compile, archive and disseminate information

concerning Alzheimer's disease for people with AD in their families, health

professionals and the public.

So we do have a clearinghouse and the ADEAR Center focuses on research-

based information on AD and other dementias. Our services include helping

our audiences find answers and new resources about Alzheimer's caregiving

06-13-12/12:15 pm CT Confirmation # 5228218

Page 38

and research through our call center, the web and responding to email and

mail and phone inquiries, developing and disseminating free publications

about Alzheimer's disease symptoms, diagnoses, related disorders, risk

factors, treatment, caregiving tips, home safety tips and research and also

making that content widely available through our Web site and other channels.

We also refer users to local supportive services through government and

private organizations like Eldercare Locator, AoA, the Alzheimer's

Association and the Alzheimer's Foundation. So Mary we're part of your

referring group who's sending people your way for the Eldercare Locator as

well as referring folks to our NIA funded Alzheimer's disease research centers

that specialize in research and diagnosis and also clinical trials and studies.

And finally we have a mission to keep our audiences up to date on the

progress of Alzheimer's research.

So next slide please.

So I'm just going to do a quick walkthrough of some of the features of our

Web site. This is the ADEAR home page which as Dave mentioned we

relaunched our Web site at the end of 2011. So you can see that the ADEAR

Center Web site is within the context of the greater NIA Web site, so all the

tools and resources that he mentioned are easily within reach from the

ADEAR Web site.

So you see the top Nav bar, the grey Nav bar provides you access to the NIA

resources and then below the ADEAR logo and name there's a dark blue Nav

bar that then will exist to provide you access to the ADEAR Center resources.

And then on the right-hand side, the bright blue bars take you to some of the

featured areas of our Web site.

06-13-12/12:15 pm CT Confirmation # 5228218

Page 39

And then as on the home page we have this tab box in the middle of the page

that provides access to quick links and hot topics for various audiences

including information about Alzheimer's, information for caregivers,

information for healthcare providers. And I just wanted to highlight on the

bottom right you can sign up for E-Alerts and down at the very bottom of this

page you can see news and highlights and FAQ's.

So now I just wanted to drill down a little bit into the Alzheimer's information

topics which you can reach from the tab box from the middle of the page or

from the drop-down menu on the blue top Nav bar called About Alzheimer's.

So next slide please.

Here are a couple of examples of the Alzheimer's information topic pages.

These are on diagnoses and causes and again I've put the URL's for each of

the pages so you can easily find them when you are - when you go back to

your computer. Each of the topics pages brings together a brief research-based

description of the topic, all the NIA publications related to that topic, a

featured research study, links to other organizations and resources and related

news, feature stories and video.

So for example on the diagnosis page there's basic information about what to

do if you're worried about memory loss, how doctors diagnose AD or other

problems, where to go for further evaluation, information about the new

diagnostic guidelines, the latest on research in this area and publications and

organizations that might be helpful.

You can easily jump to another topic using the drop-down menu at the top of

the page above the orange title that says Search an Alzheimer's Topic. One

> 06-13-12/12:15 pm CT Confirmation # 5228218

> > Page 40

information resource I particularly wanted to point out is on the bottom right

there is our Alzheimer's disease video Inside the Brain: Unraveling the

Mystery of Alzheimer's Disease. It's a four minute video which shows the

progression of Alzheimer's disease in the brain, and I think it's been widely

used as a training tool and for presentation.

So it's just a really handy thing to look at and be able to download for any

training or presentations you might want to do.

Next slide please.

The ADEAR site also features research-based information and tips for

Alzheimer's caregivers in a variety of formats covering frequent issues and

problems. A key resource that I've highlighted at the bottom of the page is our

easy to read guide Caring for a Person with Alzheimer's Disease which we

developed in collaboration with the folks at the Rush University Alzheimer's

Disease Center in Chicago.

This comprehensive guide covers a wide array of topics from learning about

the disease to coping with behavior and communication challenges to

everyday care, activities and safety to reminding caregivers and families to

care for themselves as well. It refers extensively to federal agencies and

organizations including the ones we've heard from today. And it's available -

the full guide is available online in PDF and HTML format.

It's very easily searchable and we're working on making it into shorter chunk

tip sheets on very specific topics like coping with agitation and aggression or

personality and behavior changes. We have - it's been a wildly popular guide

and has particularly has been distributed to organizations to their clients. And

06-13-12/12:15 pm CT

Confirmation # 5228218

Page 41

we've - I think we've distributed about 400,000 of these and it's consequently

out of print, but we are bringing it back into print shortly.

But in the meantime the whole guide is available online.

Next slide please.

The ADEAR site also provides information on other dementias from the

earliest stages of Alzheimer's like mild cognitive impairment to also vascular

dementia, Lewy body disease and fronto-temporal disorders. And in particular

we have recently come out I guess within the past two years with our book on

fronto-temporal disorders for patients, families and caregivers. As researchers

learn more about these other dementias there's a gap in information for

patients and families.

So we worked closely with the Northwestern Alzheimer's Disease Center in

Chicago and the Association for Fronto-Temporal Degeneration to develop

this booklet. But it is available online and in print and we're finding that it

really fills a gap for patients, families and caregivers.

Next slide please.

As Dave showed you on the main NIA site we also have a listing of the more

narrow of just the ADEAR publications on our Web site and just to reiterate

that you can view, download or order free copies of publications as they're

available. We have a wide range of publications including fact sheets on

Alzheimer's disease, basically genetics, Alzheimer's medication, legal and

financial planning or participating in Alzheimer's research.

06-13-12/12:15 pm CT Confirmation # 5228218

Page 42

And we are also quite proud of our easy to read booklets like Understanding

Memory Loss or Understanding Alzheimer's Disease and longer books and

reports that go more in depth such as Alzheimer's Disease: Unraveling the

Mystery that can be helpful as training tools for staff.

You can also find from our ADEAR publications list more general NIA

publications that includes specific information about Alzheimer's and

dementia such as talking with your doctor, our long distance caregiving

publications, So Far Away and End of Life, each of which has a section on the

special issues related to caring for someone with dementia in those particular

situations.

Much of our publication distribution is through the Aging Network and

gatekeeper organizations like the area agencies on aging and the Aging and

Disability Resource Centers, Alzheimer's Association chapters, caregiver

organizations, senior living facilities and healthcare organizations. And we are

more than happy to send quantities of publications for you to distribute to

your clients.

Next slide please.

So since research is the primary mission of NIA we want to make sure that a

key feature of our Web site is getting the word out about Alzheimer's research

news and progress. For example I think both Dave and Karen mentioned this,

you might have heard about the Alzheimer's Disease Research Summit last

month where Secretary Sebelius announced the final NAPA plan and the

launch of the awareness campaign at alzheimers.gov.

You can find the recommendations of the summit and a link to the videocast

at our site, so you can see that in the upper left there. And we also regularly

> 06-13-12/12:15 pm CT Confirmation # 5228218

> > Page 43

post news and research highlights as we - as new findings are published by

our grantees where we highlight those on our Web site. And we produce an

annual research progress report which you see featured in the bottom

screenshot. And we send our regular E-Alerts to subscribers as well as an

electronic newsletter called Connections.

Next slide please.

Another handy resource on our Web site is a list of Alzheimer's disease

research centers. These are funded by NIA, there are 29 funded Alzheimer's

disease centers around the country that conduct research on improving

diagnosis and care and search for effective treatments. They're a great

resource for patients and families providing clinical diagnosis and educational

outreach as well as clinical trials and studies.

If you were on the webinar last month you heard from two of them, the Rush

Alzheimer's Disease Center and Northwestern Alzheimer's Disease Center. So

we're really happy to be able to provide access to them through our Web site.

Next slide please.

And finally I just want to highlight the ADEAR clinical trials database. Users

can use - can go to this part of our site to find current Alzheimer's-related

clinical trials in their geographic area or a search by eligibility criteria or find

trials that are testing specific drugs or interventions. Or users can call the

ADEAR Center and we will help the person find a study that meets their

criteria.

There are currently 57 trials and studies recruiting participants in our database

including large multi-site studies like the Alzheimer's disease genetic study or

06-13-12/12:15 pm CT Confirmation # 5228218

Page 44

the AD Neuroimaging Initiative or drug trials conducted by NIA grantees and

private companies as well as smaller pilot and behavioral studies. So it kind of

runs the gamut. We're currently working on updating this interface, so the new

search interface will be launched soon and we'll be talking about it in next

month's webinar. So we're really excited to come back and talk to you about

that.

Folks can also sign up for E-Alerts to be notified when new trials are added

and so we're really eager to help folks participate in clinical trials and studies

and support our research mission.

So next slide please.

If you have any questions please feel free to contact Dave or me through the

ADEAR Center. Here's our toll-free number and/or you can email

adear@nia.nih.gov. And thank you so much for your time and attention. It

was really a pleasure.

Amy Wiatr-Rodriguez: Wonderful, thank you so much David and Jennifer. And we've got

some more questions coming in too from the web chat as well as I know we

did promise folks a chance to ask questions via audio. I know we're right

toward the end of our time, but hopefully we can get a little bit in and at least

our presenters can stay a little bit over and everything we have including a

transcript will be posted after this.

So let me ask if our operator, if (Ashley) could set up the queue for people to

ask their audio questions and then while we're waiting for that I'll ask some of

our web chat.

So (Ashley)?

> 06-13-12/12:15 pm CT Confirmation # 5228218

> > Page 45

Coordinator:

We will now begin the question-and-answer session. If you would like to ask a question please press star 1. Please unmute your phone and record your name clearly when prompted.

Your name is required to introduce your question. To withdraw your request press star 2. One moment please for your first question.

Amy Wiatr-Rodriquez: All right and while we're waiting for that to queue up we had a question come in from (Lynn) and this is for all of our presenters for Mary, Jennifer and both Davids.

If your call centers receive a call that suggests there may be elder abuse or neglect occurring and it's unlikely that the caller will contact the local APS program, would a report be made to APS?

So I'm wondering which of you would like to go first in responding to that?

David Parris: This is David Parris, oh my God we call APS probably five times a day. So yes we've probably done numerous reports. Unfortunately far too many.

Mary Osborne: And you know I would I have to second that. We are just seeing such an increase in that type of call. It's a little unsettling and, you know, we have been doing a lot of work on n4a's part to be able to begin addressing that. But we do, absolutely we will contact their local APS office.

Coordinator: And I'm showing a question from the phone lines that comes from Catholic Charities, your line is open.

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT Confirmation # 5228218 Page 46

Amy Wiatr-Rodriguez: Catholic Charities folks, if you're on you might need to unmute your phone.

Hello? You're on maybe?

Woman: Yes.

Amy Wiatr-Rodriguez: Do you have a question?

Woman: No.

Amy Wiatr-Rodriguez: No question?

Woman: No, no questions.

Amy Wiatr-Rodriguez: Okay, all right. Well why don't we move on while we're waiting for our next audio question. There was another question that came from our web chat and let me go back. With the ADEAR Center, did you have anything you wanted to add to the APS discussion?

David Burton: No actually the only thing that we would do in a case like that would be to refer the caller or the party to the APS service.

Amy Wiatr-Rodriguez: Okay but you would not make a report yourself?

David Burton: We would not.

Amy Wiatr-Rodriguez: Okay great. All right. Okay so let's move onto our next question that we had and this is a question from (Susan). She asked which of these

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT Confirmation # 5228218

Page 47

organizations provides information on religious and/or spiritual resources for

both caregivers and persons with dementia?

Jennifer Watson: This is Jennifer, I know that we provide some general information about

recognizing that spiritual practice is an important part of both taking -

caregiver taking care of him or herself or it can be an important continued

practice for the person with dementia, but we don't refer to any particular or

specific program.

Mary Osborne: This is Mary, I would have to say that we do similar - you know, when the

counselors are talking with the caregivers we might, you know, ask questions

regarding whether they have that type of support in place. But we do not

directly referral to any spiritual or faith-based organizations.

Amy Wiatr-Rodriguez: And David Parris, I don't know if you have anything else to add. I

know there's different outreach activities that I believe...

David Parris: Yes there definitely are. Certainly in our African America outreach we

certainly do use the churches as one way to reach the community in terms of

education and support. I know also on the local chapter level we work with a

number of organizations including Catholic Charities to assist with respite

care and so forth.

Some - we actually in some of the chapters at the chapter level, some of the

chapters do have support groups that are some of them faith-based affiliated,

but in that, you know, instance anytime there's a specialized group they will

make clear that it's being offered by a different group. The association itself

doesn't offer those groups, but it certainly will provide referrals to them that

deal with caregiving issues and so forth.

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT Confirmation # 5228218 Page 48

Amy Wiatr-Rodriguez: Great, thank you. Let me check in, (Ashley) do we have any other calls in the audio queue?

Coordinator: I am showing no further questions at this time.

Amy Wiatr-Rodriguez: Okay we have a couple more from the web chat, so we'll just try to do those real quickly and then conclude because I know we're a little bit over.

But again just so much jam-packed information to discuss today.

We have a question I believe this is for the ADEAR folks, if Caring for a Person with Alzheimer's Disease is also available in bulk for a caregiving organization?

Jennifer Watson: Yes.

David Burton: Yes go ahead Jennifer.

Jennifer Watson: Yes it would be, although so check with us particularly in early July. We're just now reprinting it.

Amy Wiatr-Rodriguez: Okay wonderful. And the last question I think that we'll have today to conclude came from (Cheryl) and she was saying that it seems like the information that was on the alz.org and ADEAR Web sites had a lot of duplication. Could you clarify how they are different?

Jennifer Watson: That's a really good question. So I think there's a lot of overlap, but I don't think that's necessarily a bad thing. I think the more that we can drive folks to good, credible research-based information, the better. And we're really happy and excited that alzheimers.gov is going to be a portal to do that especially with the awareness campaign that's starting.

Page 49

So I think the mission of our organizations, you know, the ADEAR Center is government-based and we are based in a research institution so we have slightly different focus than the Association, but I think we're harmonized in terms of wanting to give people the best information possible and to support people and their families as they're going through life with this disease.

Amy Wiatr-Rodriguez: Great, well thank you so much. I think with that - again I know we're over time, but I want to thank all of our presenters today. You guys had such marvelous information to share with everyone.

And I know I've already been getting requests from people and getting the slides and handouts and stuff, so hopefully it was well-received by everyone on the call and you can feel free to share this information with your colleagues, the families and the individuals that you're helping.

So thank you. If you have any additional questions, if you have any suggestions for future webinar topics or if you'd like to share information with us regarding whether you thought this webinar was helpful, we really do appreciate your feedback. You know, if it's positive, negative, indifferent, whatever, it does help us so that we know in future ones how to make sure that we're making the best use of, you know, attendee's time.

So please if you'd like to share feedback or ask questions you can email us at amy.wiatr@aoa.hhs.gov.

Thank you again for joining us today. We look forward to people joining us on our next webinar which will be Thursday, July 12 the same time 1:30 to 3:00 Eastern and it will be on Connecting the Aging Network, Individuals with Dementia and Caregivers with Research Opportunities, talking about

NWX-HHS-AOA-1 Moderator: Amy Wiatr-Rodriguez 06-13-12/12:15 pm CT Confirmation # 5228218 Page 50

clinicaltrials.gov, Trial Match and some of the other resources today. But much more information on next week's - or next month's webinar.

So thank you for joining us. This concludes today's webinar.

Woman: Thanks Amy.

Coordinator: Thank you for participating in today's conference call. You may disconnect at

this time.

END