

ARCH Network

Dear Colleagues,

Our first ARCH E-newsletter is here! Please scroll down to see the information we have compiled from various sources in the Philadelphia region. There will be a section for support groups, university clinics, research programs, and collaborative projects in the area for people with aphasia.

We also have included special input from one of our founding members as to why she thinks this is such an important initiative.

A reminder that our next group meeting will be in January of 2021.

-ARCH Network

SUPPORT GROUPS

Name / affiliation	Adler Aphasia Center
Location	First Presbyterian Church, 20 Kings Hwy E, Haddonfield, NJ 08033
Contact Information	Wendy Greenspan wendy.greenspan@temple.edu
What is the cost?	\$40 per 4 month semester (when we resume in person meetings, \$80 per 4 month semester) Scholarships available. First three meetings are free.
What time and day do you meet?	We meet on Zoom Tuesdays from 1:00 - 2:00 (when we resume in person meetings, 2nd & 4th Tuesday from 1:00 - 3:00)
What are the general activities?	Discussion on a variety of topics, education about stroke and aphasia, social events (holiday party, lunch at a restaurant).
Can partners or caregivers join?	Care partners are welcome to attend the first session. After that we ask that members with aphasia attend on their own. If the person with aphasia needs physical assistance to use the restroom, we ask that care partners remain in the building.

SUPPORT GROUPS

Name / affiliation	MossRehab Aphasia Center
Location	50 Township Line Road, Elkins Park, PA 19027
Contact Information	Nikki Benson-Watlington, 215-663-6344 <u>bensonwn@einstein.edu</u>
What is the cost?	Some programs are free, others have a nominal fee. Scholarships are available.
What time and day do you meet?	The Activity Center runs programs on Mondays, Tuesdays, and Wednesdays. Times are variable, depending on members' chosen activities. Groups are remote.
What are the general activities?	Conversation Cafe, Talking Book Club, Reta's Games Group, Virtual Variety Hour, Computer Lab, Education Programs
Can partners or caregivers join?	Members should be independent in activities of daily living or accompanied by a caregiver or co-survivor.

Name / affiliation	Philadelphia Aphasia Community at Temple
Location	Temple University
Contact Information	Gayle Dede gayle.dede@temple.edu
What is the cost?	Free
What time and day do you meet?	We meet remotely right now. Wednesdays 10:30-1:00; Thursdays 10:30-2:30; Second Saturday each month 11-12.
What are the general activities?	Various groups that involve conversation
Can partners or caregivers join?	No

UNIVERSITY CLINICS

Name	La Salle University Speech Language Hearing Community Clinic
Location	St. Benilde Tower on La Salle University Campus; Free Parking Lot K Map provided
Contact Information	Direct Number: 215-951-1888, Department Secretary: 215-951-1982
Do you provide remote services for people with aphasia?	Yes
What is your clinic schedule?	Fall, spring, partial summer semesters
Is this student run or clinician run?	Graduate Clinicians are supervised by licensed SLP
What is the fee schedule?	Free: No insurance or payment needed. Donations accepted.
Do you accept Medicare or Medicaid?	No insurance needed.
Is it all individual therapy or are there groups?	There are both individual and group sessions.

Name	Salus University Clinic
Location	Salus University
Contact Information	Eileen Hunsaker, ehunsaker@salus.edu
	Alison Finkelstein, afinkelstein@salus.edu
Do you provide remote services for people with aphasia?	Yes
What is your clinic schedule?	Based on the semester
Is this student run or clinician run?	Students under direct supervision of a clinician
What is the fee schedule?	Free
Do you accept Medicare or Medicaid?	No insurance needed.
Is it all individual therapy or are there groups?	One support group per month, as well as weekly individual therapy

UNIVERSITY CLINICS

Name	Temple University Speech-Language-Hearing Center
Location	Weiss Hall 110, 1701 N. 13th Street, Philadelphia PA 19122
Contact Information	Lisa Melvin, 215-204-4482, <u>lisa.melvin@temple.edu</u>
Do you provide remote services for people with aphasia?	Yes; assessments can be completed either virtually or in-person
What is your clinic schedule?	Academic semester
Is this student run or clinician run?	Student run with clinician supervision
What is the fee schedule?	Free
Do you accept Medicare or Medicaid?	No insurance needed.
Is it all individual therapy or are there groups?	Both; groups are only via telehealth

Name	University of Delaware Speech-Language-Hearing Clinic
Location	540 S. College Ave, Suite 102, Newark, DE 19713
Contact Information	Main Office Phone Number: 302-831-7100, Email: slhclinic@udel.edu
Do you provide remote services for people with aphasia?	We provide services and life participation groups for people with aphasia remotely.
What is your clinic schedule?	Our schedule is year round.
Is this student run or clinician run?	Our sessions are run by ASHA certified SLPs and graduate students, working in tandem throughout the session.
What is the fee schedule?	We accept most insurances, private pay, and we have a generous sliding fee schedule based on income.
Do you accept Medicare or Medicaid?	Yes, we accept both.
Is it all individual therapy or are there groups?	We offer both individual and group therapy year round. We also hold an aphasia summer intensive each year for 2 weeks.

Location of study	Penn Institute for Rehab Medicine 1800 Lombard St. Philadelphia, PA 19146
Name of project	Transcranial Magnetic Stimulation (TMS) and Speech Therapy for Chronic Aphasia
Main contact name, telephone number, and email address	Daniela Sacchetti 215-573-4336 <u>danielas@pennmedicine.upenn.edu</u>
Description of study (with type / severity of aphasia if needed)	This is an NIH-funded, double-blind study with people with aphasia (PWA) of at least 6 months duration from stroke to determine if TMS combined with Constraint Induced Language Therapy (CILT) is more effective than sham TMS and CILT. Subjects have to have aphasia from a left hemisphere stroke and no clinical or imaging evidence of a significant stroke in the right hemisphere. After an initial evaluation, subjects are seen for 10 sessions of real or sham TMS immediately followed by 60-90 minutes of CILT. They are seen back at 3 and 6 months to assess benefit.
Currently enrolling participants?	Yes. Other therapy must be terminated in order to participate.
Summary of what participant will do	Subjects will come to the lab for 2 sessions of behavioral testing followed by 10 sessions over 2 weeks of real or sham TMS for 20 minutes followed by 60-90 minutes of CILT. They will return at 3 and 6 months after the treatment for follow-up and, if possible, get a repeat MRI brain at that time.
Subject inclusion criteria for participants	 Inclusion: Ages 18-80; aphasia with WAB AQ score between 20 and 85 in the setting of a single left hemisphere stroke that occurred at least 6 months prior to enrollment; native English speaker Exclusion: had a seizure in the past 6 months; history of psychiatric hospitalizations; history of tinnitus; pregnant or plans to become pregnant; current abuse of drugs or alcohol
Subject inclusion criteria for controls	Not applicable
Length of study	Approximately 6-8 months from initial enrollment. There are approximately 22 visits with the majority of the visits concentrated in a two week period.
Compensation	\$15.00 per hour for treatment and testing as well as reimbursement of up to \$50.00 for transportation costs per visit
Parking or public transportation options	We reimburse for parking costs and can also provide transportation for participants via RideHealth (limitations may apply based on pick-up/drop-off location), which is a ride share service designed specifically for individuals needing transportation to and from hospitals and/or rehabilitation centers.
Is remote testing possible?	Some of the testing can be remote but the TMS and MRI scans require in-person visits.

Location of study	Penn Institute for Rehab Medicine1800 Lombard St.Philadelphia, PA 19146
Name of project	Transcranial Magnetic Stimulation (TMS) and Speech Therapy for Alzheimer's Disease
Main contact name, telephone number, and email address	Yuchao Wang 267-521-2060 <u>yuchao.wang@pennmedicine.upenn.edu</u>
Description of study (with type / severity of aphasia if needed)	This is an NIH-funded, double-blind study with people with Alzheimer's Disease to determine if TMS combined with Constraint Induced Language Therapy (CILT) is more effective than sham TMS and CILT. Subjects have to have a diagnosis of Alzheimer's Disease and no clinical or imaging evidence of a previous significant stroke. After an initial evaluation, subjects are seen for 10 sessions of real or sham TMS immediately followed by 60-90 minutes of CILT. They are seen back at 6 and 12 weeks to assess benefit.
Currently enrolling participants?	Yes. Other therapy must be terminated in order to participate.
Summary of what participant will do	Subjects will come to the lab for 2 sessions of behavioral testing followed by 10 sessions over 2 weeks of real or sham TMS for 30 minutes followed by 60-90 minutes of CILT. They will return at 6 and 12 weeks after the treatment for follow-up and, if possible, get a repeat MRI brain scan at that time.
Subject inclusion criteria for participants	 Inclusion: Ages 50-85; diagnosis of Alzheimer's Disease with minimental state exam (MMSE) score between 15 and 23; native English speaker; right-handed. Exclusion: had a seizure in the past 6 months; history of stroke; history of psychiatric hospitalizations; diagnosis of tinnitus; pregnant or plans to become pregnant; current abuse of drugs or alcohol.
Subject inclusion criteria for controls	Not Applicable
Length of study	Approximately 5-7 months from initial enrollment. There are approximately 22 visits with the majority of the visits concentrated in a two week period.
Compensation	\$15.00 per hour for treatment and testing as well as reimbursement of up to \$50.00 for transportation costs per visit.
Parking or public transportation options	We reimburse for parking costs and can also provide transportation for participants via RideHealth (limitations may apply based on pick-up/drop-off location), which is a ride share service designed specifically for individuals needing transportation to and from hospitals and/or rehabilitation centers.
Is remote testing possible?	Some of the testing can be remote but the TMS and MRI scans require in-person visits.

Location of study	Hospital of the University of Pennsylvania 3400 Spruce St. Philadelphia, PA 19104
Name of project	Transcranial direct current stimulation (tDCS) and Speech Therapy for Primary Progressive Aphasia
Main contact name, telephone number, and email address	Christopher HaslamorLeah Friedman267-521-1738267-507-4763chaslam@pennmedicine.upenn.eduLeah.Friedman@pennmedicine.upenn.edu
Description of study (with type / severity of aphasia if needed)	This is an NIH-funded, double-blind study with people with primary progressive aphasia (PPA) to determine if tDCS combined with Constraint Induced Language Therapy (CILT) is more effective than sham tDCS and CILT. Subjects have to have PPA and no clinical or imaging evidence of a previous stroke. After an initial evaluation, subjects are seen for 10 sessions of real (or sham) tDCS immediately followed by 60-90 minutes of CILT. They are seen back at 6 and 12 weeks to assess benefit. Thereafter, subjects cross over to receive sham (or real) tDCS. Then, they are seen back again at 6 and 12 weeks to assess benefit.
Currently enrolling participants?	Yes. Other therapy must be terminated in order to participate in this study.
Summary of what participant will do	Subjects will come to the lab for 3 sessions of behavioral testing followed by 10 sessions over 2 weeks of real (or sham) tDCS for 20 minutes followed by 60-90 minutes of CILT. They will return at 6 and 12 weeks after the treatment for follow-up and, if possible, get a repeat MRI brain scan at that time. They then cross over to receive sham (or real) tDCS and return at the same time intervals for follow-up and, if possible, a repeat MRI brain scan.
Subject inclusion criteria for participants	 Inclusion: Ages 45-80; diagnosis of aphasia attributable to PPA with minimental state exam (MMSE) score 15 or higher; native English speaker. Exclusion: seizure in the past 6 months; history of stroke; history of psychiatric hospitalizations; pregnant or plans to become pregnant; current abuse of drugs or alcohol; metal implant in the body which would exclude MRI; use of sedating medications that would make it difficult for patient to participate.
Length of study	Approximately 6-8 months from initial enrollment. There are approximately 43 visits with the majority of the visits concentrated in two 2-week periods.
Compensation	\$20.00 per hour for treatment and testing as well as reimbursement of up to \$50.00 for transportation costs per visit
Parking or public transportation options	We reimburse for parking costs and can also provide transportation for participants via RideHealth (limitations may apply based on pick-up/drop-off location), which is a ride share service designed specifically for individuals needing transportation to and from hospitals and/or rehabilitation centers.
Is remote testing possible?	Some of the testing can be remote but the tDCS and MRI scans require in-person visits.

Location of study	Temple University – Aphasia Rehabilitation Research Lab Saffran Center, 983 Ritter Annex, 1301 Cecil B. Moore Avenue Philadelphia, PA 19122
Name of project	Development of a Clinical Test of Language and Verbal Short-term Memory in Aphasia
Main contact name, telephone number, and email address	Danielle Laval 215-204-4350 <u>saffrancenter@temple.edu</u>
Description of study (with type / severity of aphasia if needed)	We are translating a research test battery for language and short-term memory (STM) in aphasia to a version that can be used by clinicians in a busy clinical setting.
Currently enrolling participants?	Soon
Summary of what participant will do	The participants will be administered a series of tests of language and verbal STM.
Subject inclusion criteria for participants	Participants will have incurred a left hemisphere stroke (single or multiple lesions, but only left hemisphere) and will demonstrate aphasia of any severity. Ages 20-80. English is primary language.
Subject inclusion criteria for controls	Ages 20-80, English is primary language.
Length of study	10 weeks
Compensation	\$10 per hour plus \$10 for transportation costs if testing is conducted on site. Parking reimbursed.
Does other therapy need to be terminated to participate in this study?	Not necessarily
Parking or public transportation options	Parking: available on site for 4.00 per hour or 20 dollars per day which is reimbursed. SEPTA subway and bus: Cecil B. Moore stop on the Broad Street line. Transportation costs will be reimbursed for up to \$10.
Is remote testing possible?	Yes. Must have access to a computer with internet and a front facing camera for Zoom sessions.

Location of study	Temple University – Speech, Language and Brain Lab Weiss Hall, 1701 N. 13th Street Philadelphia, PA 19122
Name of project	Speech Planning and Production across the Lifespan.
Main contact name, telephone number, and email address	Edwin Maas 215-204-1148 <u>slablab@temple.edu</u>
Description of study (with type / severity of aphasia if needed)	The purpose of this research is to understand the processes involved in speech production in individuals with and without speech disorders, with the goal of developing new or improving existing diagnostic methods.
Currently enrolling participants?	No
Summary of what participant will do	Participants will be asked to complete standardized and non-standardized testing, and complete a variety of experimental tasks, including naming pictures or reading words on a computer screen as fast as possible, and listening to words and nonwords to determine if they match a picture.
Subject inclusion criteria for participants	1. 18 years or older. 2. Monolingual English speaker. 3. No history of speech, language, or learning disabilities prior to onset of aphasia or apraxia of speech. 4. Normal or corrected hearing and vision. 5. Diagnosis of apraxia of speech and/or aphasia.
Subject inclusion criteria for controls	1. 18 years or older. 2. Monolingual English speaker. 3. No history of speech, language, or learning disabilities. 4. Normal or corrected hearing and vision.
Length of study	Up to 6 sessions or about 1 hour each.
Compensation	Yes
Does other therapy need to be terminated to participate in this study?	No
Parking or public transportation options	Parking lot next to building, and street parking may be available as well. Close to subway and there is a bus stop in front of the building.
Is remote testing possible?	No

COLLABORATIVE PROJECTS

Name	Project BRIDGE
Location	Northeast Region
Contact Information	Gretchen Szabo, 201-785-7089, gszabo@adleraphasiacenter.org https://www.projectbridge.online/
What is it?	Project BRIDGE is a unique project that is giving people with aphasia, their families, clinicians, and researchers the tools to collaborate on research teams. Our hope is to introduce more people to the idea of collaborative research, provide some basic training on what collaborative research is and how it works, pair with a mentor who has some experience and eventually connect them with a research team based on the area of interest.
How to get involved?	A virtual interest session will be held on December 4 th at 12:00 pm for researchers and clinicians. Please contact Gretchen Szabo to register (contact info above).

PERSONAL STORIES

The Purpose of the ARCH in Partnership

Two men stood at the bottom of a mountain perplexed at how they would reach the top. One man had the strength of three but began his journey without the proper equipment; the other did not have as much physical strength but he was always prepared and had brought the longest cord he owned. They stood side by side formulating plans in their own minds on how to conquer the mountain. After an hour, the strong man turned to the prepared man and said, "This may be an awkward trip, but if you let me use your rope, I can carry you up on my back."

-Nate (friend of the author)

In this current climate I strongly believe that we should realize we are all roots connected to the same tree. If we spent more time watering that one tree instead of attempting to all plant our own, what a magnificent tree that would be. In this analogy, ARCH is that tree. It is the home base for people with aphasia to reach out in order to be guided to the root that will best help them. ARCH's mission is to serve as an access point for people with aphasia to participate in opportunities in our region. Whether it be research, support groups, or connecting clinicians with those who need them, this group acts as a hub for transferring and sharing resources to ultimately cultivate relationships.

As a person with aphasia, three years post-stroke, I found resources in Philadelphia and New Jersey but there was no centralized space for me to find additional help. Insurance covered only a fraction of what is needed for speech therapy. But what about after that? How can people with aphasia find out about events, choirs, and support groups in one place? This is what ARCH is all about.

I recognize that my diagnosis is considered "mild" and my suffering could be much worse. For that I am grateful, which is why I will use my voice to represent those who are no longer capable of using their own. There is no better time than the present to find our purpose and coordinate our end goals to improve the quality of life for the unseen aphasia community.

Angelique Cauthorn

ARCH co-organizer

CALENDAR OF EVENTS

Next meeting: January 2021