

ARCH Network

Dear Colleagues,

Here is the next newsletter! Please scroll down to see the information we have compiled from various sources in the Philadelphia region. There will be a section for community groups, university clinics, outpatient centers, research programs, and collaborative projects in the area for people with aphasia.

Special Note: University of Delaware is having an Aphasia Summer Intensive Program for adults with aphasia. Please see page 5 for more information.

A reminder that our next group meeting will be Wednesday April 14^{th} from 6:00 pm - 7:00 pm **OR** Friday April 16^{th} from 11:00 am - 12:00 pm.

-ARCH Network

COMMUNITY 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.

COMMUNITY GROUPS

Name / affiliation	MossRehab Aphasia Center
Location	50 Township Line Road, Elkins Park, PA 19027
Contact	Nikki Benson-Watlington, 215-663-6344
Information	bensonwn@einstein.edu
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
ao you meet.	remote.
What are the	Conversation Cafe, Talking Book Club, Reta's Games Group, Virtual Variety Hour,
general activities?	Computer Lab, Education Programs
Can partners or	Members should be independent in activities of daily living or accompanied by a
caregivers join?	caregiver or co-survivor.

Name / affiliation	Philadelphia Aphasia Community at Temple
Location	Temple University
Contact	Gayle Dede
Information	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, <u>afinkelstein@salus.edu</u>
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.

SUMMER INTENSIVE

Name	University of Delaware Aphasia Summer Intensive
Who	Any adult with acquired aphasia
What	Clients will work with licensed SLPs and graduate students (individual & group therapies, client & care partner education, pre- & post-therapy assessments). The program is approximately 4-5 hours per day, 4 days per week (Tuesday-Friday) for 3 weeks.
When	June 8th – 25th, 2021 OR July 6th – July 23rd, 2021
Where	Currently, the majority of services are being performed via telepractice. Transitioning back to in-person services for the Summer 2021 will depend on CDC guidelines for management of the COVID-19 pandemic.
Cost	Financial assistance is available for costs not covered by insurance.
Contact Information	Julie McCauley, Email: mccauley@udel.edu

OUTPATIENT CENTERS

Name	Good Shepherd Penn Partners
Location	Rittenhouse, University City, Pennsylvania Hospital
Contact Information	215-349-5585
Do you provide remote services for people with aphasia?	Yes (available at Rittenhouse and University City)
Are you able to see people remotely right now?	Yes
Do you provide teletherapy in general?	Yes (depending on future insurance coverage of this benefit)
Is it all individual therapy or are there groups?	Individual (One-on-one for 60 minute sessions)
What insurances do you accept? How about Medicare or Medicaid?	Most commercial insurance, Medicare/Medicare Advantage, Medicaid- Except Health Partners

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 saffrancenter@temple.edu
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?	Yes
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 – Aphasia Rehabilitation Research Lab Saffran Center, 983 Ritter Annex, 1301 Cecil B. Moore Avenue Philadelphia, PA 19122
Name of project	TALSA measures of verbal STM as predictors of Mild Cognitive Impairment (MCI) & Dementia
Main contact name, telephone number, and email address	Dennis DeSalme 215-204-0490 dennis.desalme@temple.edu
Description of study (with type / severity of impairment if needed)	Language and memory study looking at cognitive decline, cardiovascular risk factors
Currently enrolling participants?	Yes
Summary of what participant will do	Respond to various questions on computer in yes/no format, naming pictures, repeating words
Subject inclusion criteria for participants	Diagnosis of MCI, 60+, MRI compatible, no chemo, no stroke or other major neurological disorder
Subject inclusion criteria for controls	60+, MRI compatible, no chemo, no stroke or other major neurological disorder
Length of study	Four sessions, 2 hours each session + additional MRI appointment
Compensation	\$30 for first in-person session, \$20 each Zoom session, \$70 for MRI appointment. Parking reimbursed.
Does other therapy need to be terminated to participate in this study?	No
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 slablab@temple.edu
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

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 danielas@pennmedicine.upenn.edu
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 Medicine 1800 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 yuchao.wang@pennmedicine.upenn.edu
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 Haslam or Leah Friedman 267-521-1738 267-507-4763 chaslam@pennmedicine.upenn.edu Leah.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.

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.

PERSONAL STORIES

Albert F Borris and The MON>str

Albert F. Borris is an outgoing and motivated individual who continues to overcome challenges in his life. A little over 12 years ago, Albert had a stroke that resulted in aphasia, a language disorder that has made it difficult for him to talk. Through the years he has progressed from using single words to now speaking in short phrases and full sentences. Before his stroke, Albert was a high school counselor and a writer. He wrote a variety of poems and books. *Crash into Me* was the last book he wrote before his stroke. Two years post stroke, Albert decided to write another book titled *MON>str*, about his lifelong experiences. This book was completed and recently published with assistance from Albert's good friend Cathy Driscoll in December 2020. Albert resides in New Jersey.



As a speech-language pathology graduate student at LaSalle University, when given the opportunity by my professor Dr. Husak to interview Albert, I was very eager. Throughout this interview, Albert and I both asked questions to each other and exchanged a lot of information. After reading his book and meeting with him, I learned a great deal of information about him and his personal experiences. He provided me with consent to share our conversation, so here are the interview questions and *some* of our responses:

Cassandra: When reading your book, I really was interested in what motivated you to write it.

Albert: Stroke. So, um, Ellen Hopkins-*Crank*, she motived me.

C: Who is she?

A: A best-selling author, um maybe chapter 25 and she goes like I don't know, I go stroke, so yes, so maybe 20 years ago I met her at the conference, big conference, I was writer and she was a staff person and we got hooked up and she came to my place of employment and she did a show on *Crank* three years in a row and I had my peer helpers help her.

C: Your title is Mon> str? Who is the monster in your book? Can you explain this?

A: Me and my dad. Um, yes.

C: You and your dad are the monster?

A: Yes

C. Are you able to explain this more? Why are you both the monster?

A: No. He is dead 20 years ago. One of the things he did was drink a lot and gamble a lot. Fat a lot. (using a lot of expressions and hand gestures). And he went into rehab 1986 and he stopped drinking. I am the monster because of my stroke.

C: I was really fascinated how vivid your memories were when you had your stroke. Can you tell me more about how you felt or what it was like?

A: Yes, Frustrating., angry, very angry., oh my god., so angry, furious. oh my god. maybe stroke., maybe a year after my stroke. Something happened to me, and I get depressed...

C: In the beginning, the only word you could say was "bacon." I'm sure that was frustrating for you.

A: No; thank you and maybe 10 more words. I was a vegetarian for 20 years, oh wow

C: So where did "bacon" come from?

A: Don't like fast food at all but beef, chicken, bacon, I love that, oh well

C: How did it feel when your speech and language started coming back. Do you remember when that started to happen?

A: Ooo, pretty good question, pretty good question... oooo......7 years ago I felt generous with my speech. Merciful and ...

C: Was it a relief?

A: No. I want to be back where I started from 12 years ago, so no relief but merciful

C: Do you feel like your speech and language is continuously getting better?

A: A little bit. Oh my god. Speech helps with a tiny bit (gesturing with his hands, showing a small amount) not big bit, ehhhh tiny bit

C: What do you think is helping your speech get better?

A: I think it's help, you, speech person. I think it helps the other people in the group, maybe the other volunteers, service

C: Do you think your family has helped you?

A: I live alone, but people come over sometimes, Sam 16, and Jonah 14 [Albert's sons]. Maybe too my ex-wife lives in town here with me and maybe, maybe not.

C: I noticed you dedicated your book to stroke survivors and the people who care for them. What would you say to other stroke survivors who are in your shoes?

A: Pretty good question. Very good question. Keep on trying... Keep on trying. Yes.

C: Is it important to plan ahead before you do something new?

A: Yeah. Umm. (brings out journal book) I have old goal book. Yes so um, Find a college for Samuel. Temple University and Rutgers University. I sit down with him.

C: Will we see any more books from you in the future?

A: Yes, 3.... Goal books. Write. Write a book, The Planet of the Dogs

C: So, you want to write a book called The Planet of the Dogs?

A: Yes.

C: That sounds interesting. I am interested in that. I have to read your old one-

A: Crash into me, perfect book! First thing, I got an agent, pretty good. Second thing I got an editor, pretty good. And so, I sold it for about \$30,000 and then I got a stroke. It wasn't out yet. I could have sold it for... ugh. Oh well.

C: I saw you use other forms of communication, do you usually do that, like writing?

A: I can't understand OR. Writing; maybe. Computer; perfect. Phone; maybe (using hand gestures to help explain). I go to the doctor's office and Shopping. I go there, maybe ehh. No I go there. Facetime and Facebook, Facetime. ", ah yes, this is Albert." Phone no. Zoom, pretty good.

You can read Albert's new book *Mon>str* or check out his other works on his website: https://albertfborris.com

Thank you so much Albert for this unforgettable experience with you. Just keep on trying!



Cassandra Taylor BS
Speech-Language Pathology Graduate Student
La Salle University

CALENDAR OF EVENTS

Next meeting:

Wednesday April 14th from 6:00 pm - 7:00 pm OR Friday April 16th from 11:00 am - 12:00 pm