The State of DAPS 2017
by Margaret B. Schroeder

In his January 2017 State of DAPS address, Executive Director Mike Miles provided an overview of the health of DAPS and thanked the many volunteers who make DAPS “the fairest of them all.” Many people come to DAPS after being diagnosed with Parkinson’s disease (PD), and they don’t know much about PD except that Michael J. Fox and Mohammed Ali have had it. The doctor may have said things like “chronic, neurological, and progressive,” powerful words that profoundly change a person’s life.

But there is another reason people come to DAPS. Perhaps they were referred by their doctor, or DAPS was recommended by a friend. What people learn by coming to DAPS is that they are not alone. DAPS has 375 members and sends its newsletter to 560 people and 7 doctors’ offices in the Dallas area. We provide exercise classes, speech groups, caregiver support groups, monthly general meetings, a monthly newsletter, and a growing community outreach. Our group offerings are in 12 locations around the Dallas area, including a discounted boxing class at Title Boxing Club in Allen.

It takes a lot of people to keep a 501(c)(3) like DAPS going. The Advisory Council and Board of Directors combined have 24 members. We have 24 facilitators and group leaders, 3 newsletter team members, and numerous other volunteers who work in various capacities. None of our accomplishments could be made without the support of our two professional office staff, our Executive Director (Mike) and our Administrative Associate, Jill Dominguez.

The work we do here at DAPS does more than provide group classes, informational newsletters, and comradery. We are providing hope, health, and happiness, and we’ve been doing it for 39 years. Studies have shown that socializing can provide improvements in mental health, nutrition, and physical health. One DAPS participant said, “DAPS does more, with very limited resources, than any other nonprofit organization that I know of.” Another said, “DAPS is a lifeline!” This is just the kind of feedback that keeps our volunteers coming back for more, because they know they’re having a positive influence on the lives of so many.

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FEBRUARY SPEAKER:

Sandra Lewis from LifeAtTheTable.com

Sandra Lewis had invested 20+ years in a corporate career when in 2009 she experienced what she describes as a “now or never” moment. She sold her house, put everything in storage, and enrolled in culinary school.

Today she combines her culinary expertise with her first-hand knowledge of working in corporate America to share the “secret sauce” to living a healthy life filled with meaningful work—sharing the table.

Her experience as a single mom taught her the value of gathering nightly around the table to feed the body, soul, and spirit.

In addition to her speaking, Sandra delivers an 8-hour culinary skills training program, “Kitchen Academy”, for the home cook, and also offers private cooking lessons.

Sandra shares thought-provoking content with an upbeat vibe. Audiences love her quick-witted style, and are forever changed by her timely, relevant message.

Sandra earned her BS in Mass Communications, Magna Cum Laude, from the University of Utah, and earned an AAS with honors in Culinary Arts from Le Cordon Bleu Dallas.

She is a member of the National Speakers Association, serves on the Board of the Council For Healthy Food Systems, volunteers with Nexus Recovery Center, and is Food Editor for Suburban Style Magazine.

The wonderful spaghetti, salad and dessert at January’s General Meeting was prepared and provided by the Plano location of:

HarborChase Celebrating Senior Living!

We appreciate your generosity!
State of DAPS continued from front page

“When I came here in 2015,” said Miles, “DAPS had been operating on a deficit for 15 of 17 years. It was a bold step to bring on an executive director. I’ll never forget the point in my interview process when Ben Casey said, ‘Why should we bet the farm on you?’ I’ve had a few jobs that I would’ve done for free, and this is one of them. Now, don’t go and take that to the budget committee,” he laughed.

Even though DAPS increased revenue in 2016 by over $21,000, we ended the year in deficit spending. The majority of the programs that DAPS offers are provided free of charge. That is something of which we can and should be proud. We are grateful to have reserves, due to some very generous estate gifts given to DAPS over a decade ago, which help us to keep doing all that we do. But, obviously, we can’t keep spending the reserves down. The DAPS Board has worked hard to create a “Way Forward Plan.”

The goal is to continue providing the scope and quality of programs for which we have come to be known and to continue providing those free of charge. At the same time, we acknowledge that if the reserves reach a critical level, we will have to make some tough decisions that may involve nominal fees for the classes. So, the DAPS Board and staff are working hard to establish relationships with the potential to help fund the much-needed services that DAPS provides. There are a number of ventures that are in the works, several of which could be game changers for DAPS.

“Our annual non-event is the biggest thing we do,” said Miles. “Our largest anonymous donor has given $20,000 per year during the last few non-events, and they plan to continue doing so as long as DAPS keeps its doors open. Briggs Equipment has been so kind to give us $25,000 per year. The word is getting out there that DAPS is the best-kept secret in Dallas, and we’re doing everything to change that,” said Miles. “If legacy giving isn’t something you’ve heard a lot about, I’d like to talk with you about ‘giving while you’re living,’” he said. Grants are another option for funding, but the organization must show a balanced budget in order to apply.

“Hope is one of the greatest gifts that DAPS provides, and we know it’s important not to isolate ourselves,” said Miles. “We want to spread the message that we are providing hope, health, and happiness until the cure for Parkinson’s disease is found.” Upon conclusion, Miles said, “If you would like to sign up to make a monthly or one-time donation to DAPS, please call me at 972-620-7600. Thank you for allowing me to be your executive director.”

The Future of Brain Surgery:
MRI Guided Focused Ultrasound
by Margaret B. Schroeder

Dr. Thomas Franklin, Jr., PhD spoke at our DAPS monthly meeting last November about his remarkable career that intersected the complex worlds of academia, mechanical engineering, and neurology. A broad smile came over his face when he showed us a picture of himself and a colleague accepting an award for an ultrasound patent in the mid-1980s. “Pioneers often get arrows in their backs,” he said. “We were so far ahead of the game. We were researchers; we weren’t commercial profiteers. It’s taken 30 years to get all this stuff through,” he said. Now retired in Frisco, Texas, Dr. Franklin looks back on a long and successful career that will positively impact the lives of many people for many years to come. In July 2016, the FDA approved the ExAblate Type 4000 1.0 System for non-invasive treatment of Parkinsonian tremors. In effect, the system uses ultrasound to perform brain surgery.

The history of brain surgery goes all the way back in time to the Neolithic period, when it was used to treat mental illness, epilepsy, headaches, diseases, and head injuries. Skulls with surgical holes in them have been found in archeological digs around the world, and oftentimes there is evidence that the patients were restored to health. Electrical stimulation to treat various ailments is also nothing new. In 46 AD, physician Scribonius Largus reported the use of the torpedo ray in the treatment of chronic headaches. This electric sea creature is capable of delivering a shock of up to 200 volts and lives at the bottom of the Mediterranean Sea.

From 1939 to the late 50s, a surgical procedure called pallidotomy was used successfully

DAPS would like to thank Dr. Franklin for sharing his story at our November general meeting and for helping us understand the role of ultrasound in the treatment of PD. On behalf of People with Parkinson’s everywhere, we thank him for his pioneering work in the field of MRI Guided Focused Ultrasound.
**Focused Ultrasound continued from Page 3**

on Parkinson’s patients for the treatment of tremors. Through a small opening in the skull, neurosurgeons destroy a tiny portion of tissue in the area of the brain called the globus pallidus (GPI). This area of the brain is involved in constant regulation of movement. Loss of dopamine in another area of the brain, called the substantia nigra, leads to hyperactivity within the GPI, which in turn leads to the motor dysfunction of Parkinson’s disease (PD). The destruction caused by pallidotomy benefits PD patients because it destroys the overactive neurons responsible for tremors. When the drug Levodopa was introduced in the mid 1960’s, pallidotomy took a back seat in favor of this new medical therapy.

As clinical evidence rolled in over the decades, researchers learned that medical therapy for PD becomes less effective over time. Despite many hours of research, Levodopa remains the gold standard in drug therapy because it is synthesized by the brain into dopamine, the missing chemical culprit of PD. The companion drug Carbidopa enhances the effects of Levodopa and it also reduces Levodopa’s side effects of nausea and vomiting. Even today, newly diagnosed PD patients are started on Carbidopa-Levodopa, and in the first and middle stages of the disease, the results are good. For some PD patients, however, drug therapy eventually provides little benefit in the control tremors.

In 1987, Medtronic introduced its deep brain stimulation (DBS) technology, an updated version of the pallidotomy approach. With DBS, one or two small openings are made in the skull. Microelectrodes are implanted deep within the brain, thus stimulating, rather than destroying, target brain tissue. During the surgery, very fine adjustments in the placement of the microelectrodes, called brain mapping, is done in two-millimeter increments. When the desired brain target is reached, the permanent DBS electrode is inserted and tested. This technique may be considered safer than pallidotomy, in which the destruction of brain tissue is irreversible. The primary goal of DBS is to rebalance the damaged neuronal circuits through electrical manipulation of brain structures. The microelectrodes are then connected to a computerized pulse generator which is implanted beneath the skin in the chest area below the collarbone. The wire is also implanted under the skin, thus the whole system is implanted. As soon as surgery is complete, the settings can be modified to achieve optimum control of motor symptoms. Multiple office visits may be required to adjust the settings, all of which are completely reversible.

Major surgery such as DBS carries significant risks and potential side effects. A non-invasive alternative to DBS called focused ultrasound (FUS) uses high frequency sound waves to target tissue deep within the brain. Like a magnifying glass that focuses beams of sunlight onto a single point to burn a hole in a blade of grass, FUS uses an acoustic lens to concentrate multiple beams of ultrasound onto a target deep within the brain. Target size can be as small as 1mm x 1.5mm, about the same as the head of a pin. When each individual beam passes through brain tissue on the way to its target, there is no effect. It is the convergence of multiple beams at the focal point that results in destruction of target brain tissue, similar to the lesion created by a pallidotomy. There is no opening of the skull, and therefore none of the surgical risks of DBS, and there is no destruction of brain tissue on the way to the target site deep within the brain.

Magnetic Resonance Imaging Guided Focused Ultrasound (MRgFUS) is “old fashioned surgery with a new, more controllable modality,” says Dr. Paul S. Fishman, MD, PhD in a recent webinar. This surgery takes place inside a specialized MRI machine where sonic energy is applied in gradually increasing amounts. The patient can talk to the surgical team so they can determine how much sonic energy to use in a specific target area. The MRI allows the team to see where the energy is within the brain, and they can make adjustments according to the patient’s feedback. When everyone on the team agrees that the appropriate target has been located, only then do they increase the energy level enough to create a permanent brain lesion.

MRgFUS is still considered to be in its experimental stage, with only about 700 patients so far, as compared to over 170,000 patients who have had DBS. There is currently no opportunity for retreatment with FUS, and results are known to last about a year, although researchers are continuing to monitor patients’ progress. Dr. Franklin is one of those pioneers whose name you might never hear in the Parkinson’s circles, but whose work has made a lasting and positive impact on brain surgery for many years to come. The ExAblate system uses MRgFUS and is distributed by Dallas company INSIGHTEC, allowing for many types of surgery in the areas of neurology, oncology, and gynecology.

Sources:

- www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/DeviceApprovalsandClearances/Recently-ApprovedDevices/ucm510521.htm
- https://cc.readytalk.com/cc/playback/Playback.do?id=1ceelu
- www.ncbi.nlm.nih.gov/pubmed/12061508
- www.ncbi.nlm.nih.gov/pubmed/9361073
- www.ncbi.nlm.nih.gov/pmc/articles/PMC3157831/
- www.insightec.com
Why I Give

I recently asked DAPS members why they give to DAPS. Their responses were inspiring. We have shared some of those in our newsletter and will continue to share them in various ways, as they show what DAPS really means to those we serve. Now it’s my turn to answer.

I give to DAPS because…

- I find joy in giving.
- I know that DAPS depends solely on donations for funding the large variety of programs it provides free of charge.
- I see firsthand the difference that DAPS is making in the lives of those who attend and participate in those programs.
- I hear the testimonies:
  - “My doctor says DAPS is helping me maintain my voice better than anything else I have done.”
  - “I hate it when Thursday comes around; it means that I won’t get together with my DAPS family again until Monday.”
  - “DAPS made such a big difference in the quality of my father’s life.”
  - “DAPS is a lifeline!”
  - “What a great organization and a great team. DAPS does more with limited resources than any other nonprofit organization that I know of.”

Thank you all for sharing with us your reasons for supporting DAPS. Your generous hearts keep us going, and your giving makes a difference!

Happy Valentine’s Day!

A message from Mike Miles
Executive Director

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GEMs are donors who Give Every Month.

Our GEMs are very valuable!

Sign up on the DAPS website.

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The Family of Harry Morris
would like to express its sincerest gratitude to all the special people in their lives for the outpouring of love that they have expressed in so many ways during this trying time.

-Helene Morris and Family-
MEMORIALS · HONORS · DONATIONS

DECEMBER 2016

In memory of Jackie Hickman
From: Sarah Atwood
Charles Schlinke & Scott MacPherson
Jill Dominguez
Mary Gilbreath
Tommie Harris
Lucy Martin
Mike & Donna Miles
Jesse & Aida Morales
Carrie Sadler

In memory of Jackie & Joe Hickman
From: Dottie Watts

In memory of Loy Baird
From: Betty Baird

In memory of Madelyn & Morris Wolfe
From: Sharon Blend

In memory of Eleanor June McKinney
From: Mary Cathryn Dibble

In memory of Jack Harris
From: Tommie Harris

In memory of Robert (Bob) Shaddox
From: Mike & Donna Miles

In memory of Kevin Miles
From: Mike & Donna Miles

In memory of Syl Bax
From: Sandi Pautler

In memory of Mrs. Johnnie Teague
From: Powell Baptist Church

In memory of Danforth Starr
From: Donald & Deborah Shannon

In memory of George Kilpatrick & Harry Morris
From: Cindy Weatherall

In memory of John Zdychnec
From: Teresa Zdychnec

In memory of Jerry O'Connor & Chester Maxey
From: Dee Maxey

In honor of DAPS Leaders
From: Sarah Atwood

In honor of DAPS Board of Directors
From: Jill Dominguez

In honor of Sarah Atwood
From: Lucy Martin

In honor of my courageous wife, who battles Parkinson’s every day
From: Bruce McWilliams

In honor of DAPS Newsletter Team
From: Mike & Donna Miles

In honor of DAPS Partners-in-Care
From: Lue Taff

In honor of Misty Owens
From: Anonymous

In honor of Donna Burson for her faithful, sacrificial and loving service to the Duncanville Parkinsons group
From: DAPS at Duncanville Group

In honor of Wanda Call for assisting, supporting and keeping us all updated on activities.
From: DAPS at Duncanville Group

In appreciation of SG DAPS programs
From: Anonymous

Donation to DAPS
From: Kendra Scott LLC
First Call of Dallas
Anonymous donor
Donald Bennett
Ben & Sue Casey
Annabelle Catterall
Eric Chancellor
J. Robert Dyche
Lee & Sue Hassell
Frank & Barbara Lane
Larry Levey
Louis Neeb
Bonita McElroy
Jerry McMahan
Pam & Matt Michel
Jim Neitzel
Thomas & Cecilia Pajda
Marge Riccardi
Paul Salzberger
Robert Spurgin
Hans Toffer
Jack & Joan Underwood
Kathy Wayne
Lashanda K. Dixson via Give with Liberty Campaign
Deanna Moody via Give with Liberty Campaign
Kroger Community Rewards
Anonymous individuals at December Luncheon
DAPS at Preston Hollow (Dallas)
DAPS at Trinity (Duncanville)
NON-CONTACT BOXING FOR PARKINSON’S DISEASE

Title Boxing Club of Allen
300 N. Greenville Ave. 214-644-2640
allen-greenville.titleboxingclub.com

Tuesday/Thursday...10:30 to 11:30 am
Wednesday...8:15 to 9:15 pm
Saturday...10:15 to 11:15 am

DAPS has partnered with Title Boxing of Allen to obtain reduced rates. Learn more about the program at FreeMotionPD.com. Contact the class trainer, Heidi Weimer, with any questions regarding schedules or rates.
MARK YOUR CALENDAR

**february general meeting**
Monday, February 13 - 1:00 p.m.
Speaker: Sandra Lewis, Chef
Topic: Life at the Table

**open board meeting**
Monday, February 20 - 1:00 p.m.

**march general meeting**
Monday, March 13 - 1:00 p.m.
Speaker: Paul Markowitz
Topic: Navigating the Senior Care Maze

**daps mckinney**
Tuesday, February 21 - 10:00 a.m.
Speaker: Mike Miles, Executive Director of DAPS
Topic: State of DAPS Address

**march in mckinney**
Tuesday, March 21 - 10:00 a.m.
Speaker: Sandi Pautler
Topic: Cruising with Parkinson’s

All General Membership Meetings are held at University Park United Methodist Church, 4024 Caruth Blvd., Dallas, TX 75225. For more information, call 972-620-7600.

DAPS McKinney meets on the 3rd Tuesday of every month at St. Gabriel the Archangel Church, 110 St. Gabriel Way, McKinney, TX 75070. Email mckinney@daps.us for more information.

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