

## Houston Area Parkinson Society 2017 Annual Report

**The mission of the Houston Area Parkinson Society is to improve the quality of life for those affected by Parkinson's disease through services, education and advocacy.**

Houston Area Parkinson Society celebrated a milestone year in 2017—the 200<sup>th</sup> anniversary of the discovery of Parkinson's disease. In its 43<sup>rd</sup> year of serving the greater Houston area as the only organization that provides comprehensive specialized Parkinson's programs free of charge, it currently makes its services available to an estimated 25,000 families in a vast 7,600 mile region. HAPS furthered its mission, with noteworthy achievements, and worked hard to meet the needs of those the organization serves. Pamela Skaufel took the helm as Board President in a year when Houston experienced highs and lows, from reveling in epic sports events to surviving one of the worst storms in our nation's history. No doubt, 2017 will be a year to remember.

Over the past six years, in response to the needs of the Parkinson's population in the Houston area, our organization's strategic reviews and planning at biennial Board retreats have called for growth in both program expansion and resources and revenues. However, in the interest of fiscal responsibility, our 2017 budget did not reflect an increase over the prior year's budget in spite of increases in expenses and program costs. Throughout 2017, we determined adjustments that would allow us to operate within budget, such as combining therapeutic exercise groups in cases where clients could attend another HAPS group in proximity, or relocating and expanding groups in areas with the greatest need and adding programs with thoughtful consideration. Changes were made with the guiding principle that we would not compromise the value of our services.

With the outstanding leadership and invaluable resources of time, talent and generous funding that HAPS Board members contributed, and the tremendous support we received from the philanthropic community in 2017, HAPS ended the year with only a small deficit in spite of the Hurricane Harvey disaster and the impact it had on fundraising and our annual gala, which had to be rescheduled. Board members continued to play active roles advancing the organization's mission by serving on the Special Events, Development, and Budget Committees to help raise awareness, cultivate funding and provide fiscal oversight, allowing HAPS to realize the growth and success necessary to fulfill its mission.

HAPS had a milestone year reaching a goal established at its April Board retreat of raising a million dollars to support its work with gross revenue in 2017 of \$1,004,448. Funding came from the following contribution categories: 1) 31% was generated through special events such as the Chevron Houston Marathon, Annual Awards Gala, and miscellaneous third party events; 2) 47% was raised through foundation grants; 3) 9% was received in corporate contributions; and 4) 13% was made up of individual gifts, memorial gifts and earned income.

HAPS' 2017 Gala, chaired by Hala and Joe Ahmad, honoring those with a local, national and international reach, carried forward the record attendance, outstanding support and pinnacle of success of the HAPS Galas of the last few years, and raised awareness of the organization among a new audience through a valuable partnership with Houston Public Media.

The organization's 27<sup>th</sup> Annual Educational Symposium took place in August breaking all records with nearly 450 people in attendance at the daylong conference featuring notable local and national speakers presenting sessions on what we have learned about Parkinson's over the last two centuries since Dr. James Parkinson's 1817 publication, *An Essay on the Shaking Palsy*.

HAPS filled critical gaps in care for the growing Parkinson's community providing tools to families for long term management of the disease. With a small dedicated staff of six employees, HAPS provided 66,000 service hours inclusive of all programs, reflecting an increase of 15,000 service hours over 2016. The organization expanded its therapeutic exercise and support groups in the outlying regions of Houston's metropolitan area that were lacking services for those with Parkinson's disease, bringing the number to 42 therapeutic exercise groups we provided each week and seventeen support groups each month, totaling 186 groups in 32 site locations each month by year-end.

The organization continued its broad reach through its newsletter distribution of electronic and mailed monthly informational newsletters to 5,707 households. HAPS provided educational programs presented by prestigious movement disorder specialists, neurologists and professionals with a focus on advances in treatment, disease management and quality of life. In addition to the Annual Educational Symposium, this included five Newly Diagnosed Education programs, a Summer Lecture Series, and Educational Community Presentations and Outreach. HAPS' Parkinson's Enrichment Program continued in its fourth year. An innovative national self-efficacy program was brought to Houston by HAPS, following staff and client training in Colorado in 2016, with two 9-month sessions presented to date. And a long-planned boxing program, established in fall of 2016, continued and has been so popular that a second group was added in 2017. HAPS staff members and clients traveled to Washington, DC and NYC for conferences and meetings in 2017, and for the fifth time in the twenty-one years since HAPS has been a participating charity, it was recognized with two top awards by the Chevron Houston Marathon for outstanding fundraising efforts.

### **2017 Highlights**

**Chevron Houston Marathon** In its 21<sup>st</sup> year as a participating charity, HAPS raised over \$117,000 through the efforts of 250 runners, walkers and fundraisers in the 2017 Chevron Houston Marathon. Contributions were received from 700 donors. For the second year in a row HAPS was awarded the esteemed 3<sup>rd</sup> Place Overall Top Fundraising Charity and Top Fundraising Team among 61 organizations for its hard work and accomplishments.

**HAPS Medical Advisory Board** Dr. Richard Simpson, who fulfilled the position of HAPS Medical Advisory Board Chair for twelve years, passed the torch to Dr. Joohi Jimenez-Shahed, who became Chair in 2017.

**Boxing Program** The popular non-contact boxing program HAPS added to its therapeutic exercise offerings in 2016, which incorporates a groundbreaking approach to managing Parkinson's symptoms, continued to be in high demand and a second group designed to accommodate varying levels of ability was added in 2017.

**PD SELF** This pioneering program for those who are newly diagnosed with Parkinson's was presented in its second year by HAPS. Taking place in nine regions across the US, the name, PD SELF, is an acronym for Parkinson's Disease Self-Efficacy Learning Forum.

**Parkinson's Enrichment Program (PEP)** Facilitated by HAPS Social Workers with assistance from a core group of dedicated Board member volunteers, the Parkinson's Enrichment Program continued in its fourth year. Designed to satisfy four therapeutic objectives: physical exercise, education, recreation and social interaction by hosting therapists, instructors and physicians who lead the groups in various activities, PEP met weekly for four hours each Friday during two five-week sessions.

**Collaborative Dance for Parkinson's and ParkinSING Class** HAPS carried on its steadfast partnership with Houston Ballet which began in 2009, presenting *Dance for Parkinson's* and singing classes accompanied by live music and led by performance arts professionals.

**Michael J. Fox Foundation 2017 Policy Forum** Held in Washington, DC in late February, HAPS Social Workers represented the State of Texas at this annual Policy Forum as MJFF Policy and Advocacy Volunteers. Along with HAPS clients, they joined forces with other members of the Parkinson's community to encourage changes and policy priorities related to Parkinson's disease at the federal level. Through grassroots advocacy, the group requested support for funding to implement the National Neurological Conditions Surveillance System at the Center of Disease Control which is part of the 21st Century Cures Act. Other priorities reflected were to strengthen America's health care systems by protecting critical components of the Affordable Care Act and to support the Recognize, Assist, Include, Support and Engage Family Caregivers Act (RAISE), which will direct the US Department of Health and Human Services to establish a National Family Caregiving project to assist family caregivers.

**Alliance of Independent Regional Parkinson Organizations (AIRPO)** This leadership group was established as an association of five independent Parkinson's organizations from regions across the U.S. and has grown to include eight regional organizations. The Alliance developed out of a series of meetings which began in 2009 that provided opportunities for sharing ideas, information and resources, enabling member organizations to better deliver quality services to those living with Parkinson's disease in their regions and collectively benefit the greater Parkinson's community. In its fourth year since officially forming as AIRPO, the group convened in NYC at a spring meeting hosted by the Parkinson's Foundation, focused discussions on programs that improve life for those we serve, and the changing landscape of the national organizations and resulting impact on the Parkinson's community.

**Biennial Board Retreat** HAPS had spirited discussions on goals, growth of the organization and strategic planning on all levels at the biennial Board retreat strategic planning session led by Phillip Weiss, executive coach, facilitator and organizational consultant, which took place in April and included members of the Board of Directors and the Chair Medical Advisory Board.

**Pasta for Parkinson's** The Original Carrabba's restaurants donated a portion of each sale of the featured menu item, *Ken Beckett's Meat Ravioli*, during the month of April. In its third year, this initiative, held in recognition of Parkinson's Awareness Month, raised funding and priceless community visibility.

**Painting with Parkinson's** Nearly fifty HAPS artists participated in a painting event led by art instructor Susan Wingfield that honored World Parkinson's Day, Dr. James Parkinson's birthday and April as Parkinson's Awareness Month.

**Kerr/Thorp Challenge** This invaluable fundraising program in its 6<sup>th</sup> year raised nearly \$44,000 in individual and corporate funding over the summer months. Rob Kerr and Jim Thorp were honored at the organization's 2015 gala for their continued support of this program which totals \$240,243 it has raised since it began and which provides an important incentive for clients who want to give back to HAPS in thanks for what we do to improve their lives, allowing them the satisfaction of knowing they have been able to double the amount of their gifts.

**Seventh Annual Summer Lecture Series** HAPS continued its Summer Lecture Series and featured two extremely well-attended presentations by professionals in the field on pertinent Parkinson's topics which segued into the Annual Educational Symposium in August. Each year attendance has grown, doubling in recent years. This year's series was videotaped and archived.

**Annual Education Symposium** With 435 people in attendance, this biennial event took place in August in a new venue breaking all records in attendance, content, allied health participation and sponsorship with prestigious local and national speakers presenting sessions on advances and breakthroughs related to Parkinson's over the last two centuries since the disease was discovered.

**Hurricane Harvey** The entire city of Houston felt the destructive impact of Hurricane Harvey including clients, group leaders, staff and Board members who make up the HAPS family. HAPS staff responded with immediate messaging through social media, the internet, email and phone, checking on the Parkinson's community and letting people know we were available to help them. Groups were canceled for two weeks and there was an enormous outpouring of support from the community which made it possible for the organization to compensate group leaders with the pay they would have received if the groups had not been cancelled, and provide assistance to clients by covering repairs, cleaning supplies, restocking groceries and filling miscellaneous needs related to the storm.

**Changing the Face of Parkinson's Gala** The fall Annual Awards Gala, rescheduled because of Harvey, was attended by 340 people, skillfully chaired by Hala and Joe Ahmad, and ranked as one of the top four HAPS galas in gross revenue since 2004 when the event began. Izzy and John Schulte led the way chairing the Young Professional Host Committee. Honorees Robert Flatt, World Parkinson Coalition, and Diane Rehm, who was also keynote speaker, were recognized for the difference they have made in the lives of those with Parkinson's disease with the Lillie Cullen Quality of Life Award, Roy H. Cullen Quality of Life Award and President's Award, respectively. Three days after the event, HAPS welcomed a new member into the HAPS family when longtime staff member Celeste Harris gave birth to a baby boy.

**Third Party Events** Generous funding was contributed to the organization by people and businesses in the community who held events to raise money to support HAPS efforts. Among those were: the Angela Morris Jewelry Holiday Event, Playing for Parkinson's, the Justin Curren Memorial Golf Tournament, and Calpine's 13<sup>th</sup> Annual Texas Regional Charity Golf Tournament.

**HAPS Holiday Sing Along** Continuing the tradition in its 5<sup>th</sup> year, HAPS and Houston Ballet presented a Holiday Sing Along with over 70 people of all ages participating in fun, festive holiday singing and vocal instruction. This event is modeled after HAPS' ParkinSING class.

We thank the Board members who have completed their terms as officers and directors and will move to the Board of Advisors for the exceptional guidance and unwavering support they have provided. We look forward to the new and fresh perspectives that all of the members of the HAPS Boards will bring to their roles leading the organization as we carry out the HAPS mission.

In 2018, as we define our direction and goals, HAPS will strive to broaden its base of funding and cultivate partnerships within the community that support the organization's efforts. Moving forward with a strong financial position, we will, nevertheless, be mindful of the challenges of a recovering local economy and an uncertain global economy, and will continue to be nimble and thoughtful in our strategies related to providing valuable services and programs to meet the growing needs of the Parkinson's community—as HAPS has done for over four decades.

Considered a national model among independent regional Parkinson's patient support organizations, HAPS will continue to be guided by its mission and will go forward with purpose, relevance, innovation and a close connection to the community it serves.