

# Survey of Parkinson's Organizations

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# Disclaimers/Disclosures:

- The data here is all publicly available. My main source was Charity Navigator.
- All opinions are mine and mine alone based on my personal experiences and analysis.
- This is not guaranteed to be a complete list.
- This only includes 501(c)(3) organizations
- I am on the board of the Parkinson's Association of the Rockies.
- I receive no compensation from any of these groups.

# What is a 501(c)(3) Organization?

- An entity organized and operated exclusively for the benefit of charitable, religious, educational, scientific, literary, testing for public safety, fostering national or international amateur sports competition, and preventing cruelty to children or animals. No earnings may benefit any private shareholder.
- It may not attempt to influence legislation as a substantial part of its activities and it may not participate in any campaign activity for or against political candidates.
- I believe (but am not certain) that care must be taken that funds support the charter of the organization. E.g., An organization that supports a Little League team cannot decide to spend most of its funds on rescuing dogs.

# Big Charities (and some disease focused ones)

Charity	Size
Feeding America	\$3.3B
American Red Cross	\$2.7B
Dana-Farber Cancer Institute	\$1.8B
City of Hope	\$1.8B
ALSAC - St. Jude Children's Research Hospital	\$1.7B
Direct Relief	\$1.6B
Smithsonian Institution	\$1.4B
Americares	\$1.2B
World Vision	\$1.2B
Shriner's Hospitals	\$900M
American Cancer Society	\$800M
American Heart Association	\$800M
Alzheimer's Association	\$400M

# Interesting things

- “Non-profit” doesn’t mean it is free or all volunteer
  - MJFF chair makes \$900k, CEO makes \$850k
  - MJFF paid marketing contractor \$500k and advertising contractor \$400k
  - Key metric: % of expenses used on delivering programs
    - *>75% is good. >%50 is bad*
- Lots of growth
  - 18 of 29 companies grew more than 10% annually in last two years.
- Lots of variability
  - Parkinson’s Institute and Clinical Center was over \$9M in 2017. It’s now out of business
  - Davis Phinney grew 45% from 2019 to 2020, but almost all of that was one bequeathment.
  - Parkinson Association of The Carolinas went from \$1.4M to \$230k in one year.

# The Parkinson's Landscape

- Total Spent on Parkinson's 501(c)(3) ~ \$240M
  - Michael J Fox Foundation: \$162M (67%)
  - Parkinson's Foundation: \$40M (17%)
  - American PD Association: \$11.5M (5%)
- Of remaining 10% (~\$26M)
  - \$12M goes to 5 National Organization
  - \$14M goes to 20 Regional Organizations

# Michael J Fox Foundation

- Vision: “Eliminate Parkinson's disease in our lifetime.”
  - “Dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today.”
- Strengths:
  - Funding, name recognition
  - Research Support for understanding and treating PD
  - Clinical Trial Support
  - Political Clout/Advocacy: Parkinson’s Policy Forum
- Not strengths:
  - Little local presence
  - Too strong a focus on a cure rather helping existing PWP?

# Parkinson's Foundation

- “Makes life better for people with Parkinson's disease by improving care and advancing research toward a cure.”
- Strengths:
  - Provide excellent set of resources for PWP
  - Center of Excellence Program
  - Parkinson's Outcomes project
  - Cosponsor of Parkinson's Policy Forum
- Not strengths
  - Little local presence
  - Aggressive fundraising



# American PD Association

- “Every day, we provide the support, education, and research that will help everyone impacted by Parkinson’s disease live life to the fullest.”
- Strengths:
  - Detailed scientific information about Parkinson’s
- Not Strengths:
  - Spend a lot on fundraising, reducing program funding
  - Not a lot of local presence

# Other National Organizations

- Davis Phinney - \$4.2M
  - Victory Summit Events, Every Victory Counts Book
- Parkinson's Voice Project - \$3M
  - Speech Therapy Programs
- Parkinson's Research Foundation - \$2M
  - Focus on patient education and free onsite and online services (very high fundraising costs)
- Parkinson's and Movement Disorder Alliance- \$1.8M
  - Developed a Care and Support Ecosystem©
- Rock Steady Boxing - \$1.7M
  - Franchise style Parkinson's Boxing/Fitness Training

# Regional Organizations

- Northwest\*, Houston\*, Florida\*, Michigan\*, Washington D.C., Oregon, Rockies\*, Brian Grant (Oregon), Philadelphia, New Jersey, San Diego\*, SW Florida, Wisconsin, Western Pennsylvania\*, Oklahoma, Kentuckiana, Alabama\*, Dallas\*, Northern California\*, Carolinas\*
  - \* Members of AIRPO (Alliance of Independent Regional Parkinson's Organizations)
  - Average of \$677k (min \$230k, max \$1.3M)
  - Generally, these all sponsor exercise classes, support groups, educational events in their regions.

# Backup

State - City	Name	Year	Revenue	2 year Growth	% of Funding	Program Expense
NY - New York	Michael J Fox Foundation	2019	\$ 162,000,000	56%	67%	86%
FL - Miami	Parkinson's Foundation	2020	\$ 40,200,000	32%	17%	84%
NY - Staten Island	American Parkinson Disease Association	2020	\$ 11,500,000	11%	4.8%	68%
CO - Boulder	David Phinney Foundation	2020	\$ 4,170,000	65%	1.7%	76%
TX - Dallas	Parkinson's Voice Project	2020	\$ 3,010,000	-6%	1.3%	86%
FL - Sarasota	Parkinson Research Foundation	2020	\$ 1,940,000	26%	0.8%	47%
AZ - Tuscon	Parkinson & Movement Disorder Alliance	2020	\$ 1,800,000	107%	0.7%	80%
IN - Indianapolis	Rock Steady Boxing	2019	\$ 1,680,000	22%	0.7%	74%
WA - Mercer Island	Northwest Parkinson's Foundation	2018	\$ 1,300,000	5%	0.5%	
TX - Houston	Houston Area Parkinson Society	2019	\$ 1,150,000	32%	0.5%	65%
FL -Sarasota	Neurochallenge Foundation	2020	\$ 1,140,000	186%	0.5%	91%
MI - Bingham	Michigan Parkinson Foundation	2019	\$ 1,100,000	67%	0.5%	76%
Washington DC	Parkinson Foundation of the Nat Cptl Area	2020	\$ 1,050,000	13%	0.4%	77%
OR -Beaverton	Parkinsons Resources of Oregon	2019	\$ 1,020,000	-5%	0.4%	
CO -Denver	Parkinson Association of the Rockies	2019	\$ 934,000	22%	0.4%	
OR - Portland	Brian Grant Foundation	2019	\$ 851,000	28%	0.4%	
PA - Philadelphia	Parkinson Council	2019	\$ 710,000	7%	0.3%	
NJ - Princeton	Parkinson Alliance	2020	\$ 624,000	-22%	0.3%	
FL- Naples	Parkinson Association of SW Florida	2020	\$ 598,000	33%	0.2%	
WI - Milwaukee	Wisconsin Parkinson's Association	2019	\$ 543,000	48%	0.2%	
PA - Philadelphia	Parkinson Foundation of Western PA	2019	\$ 532,000	-19%	0.2%	
OK - OKC, Tulsa	Parkinson Foundation of Oklahoma	2020	\$ 429,000	-20%	0.2%	
KY - Louisville	Parkinson Support Center of Kentuckiana	2019	\$ 422,000	64%	0.2%	
AL - Brimingham	Parkinson's Association of Alabama	2020	\$ 402,000	12%	0.2%	
TX - Dallas	Dallas Area Parkinsonism Society	2019	\$ 332,000	35%	0.1%	
SC - Greenville	Greenville Area Parkinsons Society	2020	\$ 331,000	48%	0.1%	
CA- San Diego	Parkinson's Association (San Diego)	2020	\$ 274,000	60%	0.1%	
CA- Folsom	Parkinson Association of Northern CA	2019	\$ 264,000	67%	0.1%	
NC - Charlotte	Parkinson's Association of the Carolinas	2020	\$ 230,000	-88%	0.1%	