

Inside Philanthropy



The State of
American Philanthropy

Giving for
Neuroscience
Research

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ABOUT INSIDE PHILANTHROPY

Inside Philanthropy is a digital media site that covers the world of charitable giving. We report daily on foundations, major donors, and trends in philanthropy. Through our GrantFinder resource, we also profile and track thousands of funders working across key issue areas and geographic regions. Inside Philanthropy is supported by reader subscriptions and advertising. We do not receive funding from any other source. Learn more at insidephilanthropy.com

ABOUT THE STATE OF AMERICAN PHILANTHROPY

The State of American Philanthropy is a series of background papers on important topics and trends in U.S. philanthropy. The papers draw on past research and reporting by IP writers, as well as new interviews, grantmaking data, and other sources. Learn more at insidephilanthropy.com/state-of-american-philanthropy.

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EXECUTIVE SUMMARY

This brief explores the giving of major donors, private foundations, grantmaking public charities, corporations and community foundations to U.S.-based nonprofit neuroscience research organizations.

Philanthropy can constitute a significant percentage of neuroscience research organizations' revenues, although reliance on donations varies considerably from one organization to another. The field's largest source of funding comprises affluent donors whose one-time gifts or commitments can eclipse the annual grantmaking budget of a major private foundation.

Buoyed by a surging stock market, a vast ecosystem of funders disbursed hundreds of millions of dollars to accelerate the pace of research into preventing, detecting and treating neurological disorders of the brain, spine and nervous system over the past 30 years. This support frequently takes the form of high-risk investments that fall outside of the purview of federal agencies and pharmaceutical companies.

This brief explores the following long-term factors and trends affecting neuroscience research funders and fundraisers:

Who's Giving

- Affluent individual donors play a leading role in the nonprofit neuroscience research ecosystem. Within this demographic is a subset of relatively less-affluent donors who otherwise generally give within their regions and who represent the charitable backbone for most neuroscience research organizations.
- Private "legacy" foundations that receive a great deal of attention in many other giving areas provide less financial support for neuroscience research than major individual donors, but a few are committed to supporting cutting-edge research, as well as pushing for more equitable health outcomes across the field.
- Corporate philanthropy for neuroscience research primarily takes the form of donations to patient advocacy organizations, which, in turn, regrant the support to research organizations.
- Community foundations support neuroscience research organizations through discretionary grantmaking and donor-advised funds (DAFs), which constitute the majority of their funding.

Who's Getting

- A substantial portion of philanthropy dollars flow to patient advocacy organizations with broad charters that also include advocacy, education and patient care. These organizations regrant support to front-line organizations conducting research.
- Funders also directly support organizations conducting neuroscience research at universities, which constitute the largest recipient type, as well as hospitals and nonprofit medical clinics.

The Big Issues and Funding Trends

- Funders' top priorities include understanding the brain's complexity and how basic research can yield insights that apply to multiple fields, pursuing advancements in the biology of aging and cognitive aging, and developing diagnostic tools to enable early detection of neurological disorders.
- The sector's dominant funding strategies apply a venture philanthropy mindset to accelerate the return on high-risk, high-reward treatments, target interventions to bring promising but underfunded treatments to market, and drive collaboration across a field replete with administrative, regulatory and funding constraints.

Equity in the Sector

- Recognizing that an increasing number of Americans will be diagnosed with a neurological condition as the population lives longer, funders are particularly concerned about impacts across specific ethnic and racial groups that have disproportionately higher incidence rates for certain diseases.
- In an effort to boost equitable health outcomes, neuroscience funders are tackling the pervasive representation gaps in clinical trials for drugs that treat neurological disease, addressing the underlying economic and social issues that contribute to health disparities, and embedding equity into organizations and their grantmaking strategies.

Looking ahead, philanthropy's role in the neuroscience research space is likely to become even more critical as federal support falls behind inflation and treatment costs escalate, especially given the projected increase in incidence rates. Funders and research professionals I spoke with identified a set of emerging opportunities for grantmakers, such as educating donors about the importance of basic research, expanding efforts to promote data sharing, closing representation gaps in clinical trials and ramping up support for prevention research.

Introduction

In 2017, Bill Gates published a blog post titled “Why I’m Digging Deep into Alzheimer’s.” As the richest man in the world at the time, Gates certainly did not fit the mold of a “middle of the pyramid” or even billionaire donor who typically supports neuroscience research organizations. Nonetheless, his essay succinctly encapsulated why and how funders – billionaire or otherwise – were supporting cutting-edge work in the field.

“Thanks to scientific advancements, fewer people die young from heart disease, cancer and infectious diseases,” he wrote, noting that his father was about to turn 92. But as people live longer, society will be facing unprecedented demands for prevention, diagnosis and treatment. Researchers expect the number of people living with [Alzheimer’s disease](#) to triple to 153 million people by 2025, while the World Health Organization said that the worldwide cost of dementia—a general term for the impaired ability to remember, think or make decisions, rather than a specific disease—could double to \$2.6 trillion by 2030. “Absent a major breakthrough,” Gates wrote, “expenditures will continue to squeeze healthcare budgets in the years and decades to come.”

Federal officials also grasped the sense of urgency. In 2022, Julie Collens, a board member of the Alzheimer’s Association’s San Diego/Imperial chapter, noted that National Institutes of Health (NIH) funding for Alzheimer’s and dementia research quadrupled over the last 10 years to \$3.2 billion, an increase “that is greater than any other disease area over the same period.”

Increasing attention and resources still don’t match the size of the obstacles to surmount in the daunting field of neuroscience research. Funders understand that overall levels of support remain insufficient, and do not account for the cumulative financial and quality-of-life impacts for tens of millions of Americans afflicted with the conditions noted below.

This State of American Philanthropy brief focuses on basic neuroscience research and research specifically focused on conditions such as:

- Acute spinal cord injury.
- Alzheimer’s disease.
- Amyotrophic lateral sclerosis.
- Autism.
- Brain tumors.
- Epilepsy and seizures.
- Multiple sclerosis.
- Muscular dystrophy.
- Parkinson’s disease.

Research into the underlying complexity of the brain often yields findings that apply to disorders that fall under the rubric of mental health. “There’s a lot of interconnectedness and comorbidities, and when you fund this kind of research, you sometimes get findings that you didn’t expect,” said CURE Epilepsy CEO Beth Lewin Dean, who noted that translational research into epilepsy can overlap with other neurological conditions like depression and bipolar disorder.

That said, the medical field typically acknowledges a distinction between neurology, which focuses on physiological illnesses, and psychiatry, which specializes in psychological disorders. This brief

will primarily center on giving for organizations conducting research into the neurological disorders of the brain, spine, nervous system and nerves. A separate IP white paper, “[Giving for Mental Health](#),” looks at funder support for research and treatment for conditions like depression, anxiety, bipolar disorder and schizophrenia.

Gates, in his blog post, announced he had invested \$50 million in the Dementia Discovery Fund, a private entity that complements the work of major pharmaceutical companies “by supporting startups as they explore less mainstream approaches to treating dementia.” Here, Gates articulates a venture philanthropy mindset galvanizing funders in the neuroscience research field. Unlike federal agencies that must answer to taxpayers or pharmaceutical companies that answer to shareholders, private funders have more latitude when it comes to supporting high-risk investments that have longer odds of success but could generate major impact.

Gates also noted that his interest in tackling Alzheimer’s disease is a deeply personal one. “This is something I know a lot about, because men in my family have suffered from Alzheimer’s,” he wrote. He isn’t alone. As McKnight Brain Research Foundation Chair Emeritus J. Lee Dockery told IP, “So many of the opportunities for [neurological] diseases are funded by benefactors who’ve had a relative or someone that they know that has been a victim of that disease, so they support that cause, and it’s justified that they do so.”

Lastly, Gates is representative of the kind of affluent mega-donors who have come to dominate the space in recent years. A Wall Street or Silicon Valley donor’s one-time \$50 million gift or pledge can eclipse the annual grantmaking of a prominent

research foundation. More so than other funders, major donors frequently earmark a percentage of large gifts for capital purposes, such as constructing a new research or patient care facility. For the purpose of this brief, we will primarily focus on support to organizations conducting research for treatments and preventative measures.

All told, Gates’ journey as a benefactor of Alzheimer’s research is a familiar one. Concerned with ballooning costs to the healthcare system and sluggish federal funding, donors, many of whom have a loved one suffering from a debilitating neurological condition, are bankrolling cutting-edge research with the goal of bringing innovative treatments and diagnostics to market.

The field faces a litany of formidable challenges, the most prominent being researchers’ relative ignorance of how the brain operates. “The brain is the most complex system known to humankind,” Kavli Foundation Life Sciences Director Amy Bernard told IP. “We still don’t have a system of understanding the brain as an organ like the way we do a kidney or a lung.”

To this point, experts are calling on philanthropy to boost funding for basic research that can unlock clinical breakthroughs across neurological specialties. Funders are also expanding efforts to promote data sharing, close demographic representation gaps in clinical trials and bankroll innovative prevention research that links neurological conditions to behavioral and environmental factors.

Speaking to IP, Parkinson’s Foundation President and CEO John Lehr spoke for the countless number of funding leaders who are pushing the neuroscience field forward with a profound sense

of urgency. “The world’s population is aging and technological and medical breakthroughs will only strengthen this trend, and as a result, more people will be diagnosed with age-related neurological disorders like PD and Alzheimer’s,” Lehr said. “Addressing these diseases through research should have enormous consequences, not just for those living with the diseases and their loved ones, but for society as the cost of care is increasing in both financial and human terms.”

The Lay of the Land

Who's Giving

The ecosystem of philanthropy supporting neuroscience research consists of individual donors, private foundations (including family foundations), community foundations and corporate funders. Unlike most other areas of giving, like education and health more generally, major individual donors lead the way in giving for neuroscience research.

It is always difficult to quantify support from individual donors for neuroscience research (or any other field, for that matter) with precision because recipient organizations are not required to list individual donations on Forms 990. However, strong anecdotal evidence, along with donor appreciation lists on annual reports, point to individual donors' disproportionately large footprint in the neuroscience research space.

While not comprehensive, the Chronicle of Philanthropy's Big Gift Database and Philanthropy News Digest track publicly announced gifts. A search of giving in 2020 and 2021 reveals 32 gifts or commitments totaling approximately \$600 million in support for research or the construction of research facilities in fields like Alzheimer's and Parkinson's disease, dementia, autism, ALS and the broad fields of "brain disorders" and "neurology research." This figure significantly exceeds the total combined research grantmaking to domestic organizations in the most recent available tax filings from major private funders like the Michael J. Fox Foundation for Parkinson's Research (\$131 million), Alzheimer's Drug Discovery Foundation (\$30 million) and National Multiple Sclerosis Foundation (\$27 million).

As the pandemic subsides, donors are giving even more in this area. Major gifts and commitments in 2022 include \$75 million from Nike co-founder Philip Knight and his wife Penelope to establish the Phil and Penny Knight Initiative for Brain Resilience at Stanford University and a \$150 million commitment from billionaire T. Denny Sanford to establish the UC San Diego Sanford Stem Cell Institute with the goal of developing better treatments for diseases including Alzheimer's and Parkinson's.

10 Neuroscience Research Funders to Know

ALS Association

American Brain Foundation

Alzheimer's Association

Autism Speaks

Alzheimer's Disease Research Foundation

Alzheimer's Drug Discovery Foundation

Michael J. Fox Foundation for Parkinson's Research

Muscular Dystrophy Association

National Multiple Sclerosis Society

Parkinson's Foundation

The explosion of giving through donor-advised funds (DAFs) also underscores individual donors' enormous footprint in the space. Fidelity Charitable is the largest holder of DAFs in the country, having disbursed over \$61 billion in grants since launching the first national DAF program in 1991. According to Fidelity Charitable's [2021 Giving Report](#), the Alzheimer's Association was the 14th most popular charity in 2020 and the seventh most popular charity in Fidelity Charitable history.

In a separate analysis, IP collected Candid data on giving for major neurological conditions. While Candid's methodology does not specify whether gifts were earmarked for research purposes, the analysis nonetheless underscores an outsized role for individual donors.

The 10 largest funders gave a total of \$434 million from 2015 to 2019. Of this amount, \$201 million (46%) came from family foundations like the Simons Foundation, the giving vehicle of hedge fund billionaire Jim Simons, and the Sergey Brin Family Foundation, the giving vehicle of the Google cofounder. Eighty-six million dollars (20%) flowed from Fidelity Charitable and Schwab Charitable, financial services firms that manage donor-advised funds, which are proxies for individual giving. Even if 25% of the \$86 million in gifts from Fidelity and Schwab flowed to neuroscience research, the amounts would rival the annual grantmaking of some of the field's largest private foundations. Moreover, the Candid data

does not track gifts or commitments made by donors separate from their family foundations.

Some of the field's largest foundations based on the total amount of research grants disbursed according to the most recent tax years are the Michael J. Fox Foundation for Parkinson's Research (\$98 million), the Alzheimer's Drug Discovery Foundation (\$30 million) and the National Multiple Sclerosis Society (\$27 million).

Family foundations in which the living donor or spouse is the grantmaker's primary decision maker, like the Simons Foundation and Sergey Brin Family Foundation, are also major vehicles for individual giving. In 2022, Daniel and Phyllis Epstein gave \$25 million each to the University of Southern California and UC San Diego to establish the Epstein Family Alzheimer's Research Collaboration through their Epstein Family Foundation. Dan is the founder of the ConAm Group, a San Diego-based property management company, and a USC alumnus. Phyllis serves on many regional leadership boards, including the San Diego Symphony and the Lawrence Family Jewish Community Center.

Major donors direct their support to university research centers, private research institutions, public and private hospitals, and public charities that can regrant the support. While a substantial portion of funding continues to flow to institutions in major metropolitan areas, the growth of regional wealth has extended donor giving beyond the usual affluent coastal enclaves. In 2020, philanthropist Joy Chambers-Grundy and the late Reg Grundy committed \$6 million to the University of Nevada, Las Vegas to establish a center dedicated to researching the treatment of neurological disorders. A year later, venture capitalist Lee Fixel and his wife Lauren gave the University of Florida Health in

Foundation Spotlight



For every \$1 spent by the Michael J. Fox Foundation (MJFF), \$0.88 goes to support its programs. Its preclinical portfolio investigations have led to over 20 early-stage therapeutic programs, more than 15 disease-modifying interventions from its clinical program are currently in the clinical trial stages, and the MJFF-sponsored Parkinson's Progression Markers Initiative has been downloaded 1.7 million times since it launched in 2010. MJFF receives a wide range of support from donors such as Sergey Brin and Karen Pritzer, as well as, nonprofits such the Grove and Rainwater Charitable foundations.

Gainesville \$25 million to spur research by expanding the Norman Fixel Institute for Neurological Diseases.

Our research was not able to pin down an average percentage of research dollars that organizations derive from private philanthropy versus government funding. As far as the broader medical research space is concerned, the Milken Institute found that private philanthropy comprises **less than 3%** of overall spending on medical R&D in the United States.

It's important to frame this statistic within the broader funding landscape. While the U.S. has continued to devote approximately the same percentage of GDP to the funding of scientific research, other countries have increased their relative investment in science in recent years. Venture capital has also shifted significantly to other countries. As a result, the U.S. is not the dominant leader in science that it was in the late 20th century, said Bob Conn, the former president and CEO of the Kavli Foundation, a Los Angeles-based science and medical research funder. "Government funding is very large and we absolutely need it, but budgets are not rising at the federal level," Conn told IP in 2021. "America needs to recognize and look at the future with this (philanthropic money) in mind, and look at its policies with all this in mind. Philanthropy will have a much bigger role to play in the coming years than it has ever had."

Among grantmaking public charities and private foundations supporting neuroscience research, specific interests vary considerably. Those interests hinge on many factors, such as the extent to which research is part of its broader mission or whether the funder focuses on a specific disease/condition or

on neurological functioning writ large. Rather than paint all public charities and private foundations with a broad brush, IP has identified the following subsets of funder types providing support to neuroscience research organizations.

Patient advocacy organizations. These institutions focus on a broad swath of activities like research, education, prevention, patient care and advocacy. Given this broad charter, these institutions typically allocate a smaller percentage of operating expenses toward research when compared to funders exclusively devoted to research.



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—Bob Conn, former president and CEO, Kavli Foundation

For the fiscal year ending June 2021, the Parkinson's Foundation had \$42 million in revenues and awarded \$20 million in grants. Of that amount, it earmarked 42% for medical and clinical research grants (\$8.5 million), with the balance flowing to community engagement, patient education and professional training. The \$8.5 million allocated for research constituted 19% of the foundation's total expenses.

Since some patient advocacy organizations tend to have substantial revenues, their grantmaking budgets tend to be relatively large and impactful. For example, the National Multiple Sclerosis Society

had \$155 million in revenues according to the most recent available tax documents. While it only earmarked 17% of expenses toward research, the amount – \$27 million – places the society among the field’s largest funders.

Prominent patient advocacy organizations include the Alzheimer’s Association, Amyotrophic Lateral Sclerosis Association, Michael J. Fox Foundation for Parkinson’s Research, Muscular Dystrophy Association, Epilepsy Foundation of America and Autism Speaks.

Disease-Specific Research Funders. These entities’ primary activity is funding research for a specific neurological condition. As a result, they devote a substantial portion of operating expenses toward grants. For the fiscal year ending Dec. 2019, the Alzheimer’s Drug Discovery Foundation disbursed \$30 million in grants to domestic research organizations and individuals. This figure accounted for 91% of the foundation’s total expenses. Another funder, the American Brain Foundation, allocated \$2 million in research grants for the fiscal year ending Dec. 2020, constituting 99% of its expenses.

Other disease-specific funders include the Alzheimer’s Disease Research Foundation, Alzheimer’s Foundation of America, the Brain & Behavior Research Foundation, CURE Alzheimer’s Fund and CURE Epilepsy.

Medical Research Funders. This group consists of private and family foundations that provide funding for neuroscience research as part of a larger giving portfolio. Examples include American Federation for Aging Research, Bill & Melinda Gates Foundation, BrightFocus Foundation, Chan Zuckerberg Initiative (technically an LLC, not a

private foundation), Conrad N. Hilton Foundation, Doris Duke Charitable Foundation, Foundation for Neurological Diseases, Goizueta Foundation, Gordon and Betty Moore Foundation, JPB Foundation, Kavli Foundation, Marcus Foundation, New York Stem Cell Foundation, Once Upon a Time Foundation, Simons Foundation, Rainwater Charitable Foundation, the William K. Warren Foundation and the W.M. Keck Foundation.

It is beyond the scope of this brief to explore giving for activities unrelated to research, such as community outreach, construction projects, patient care and financial assistance, or endowments unrelated to research.

Who’s Getting

Funders support research at university and academic medical centers, hospitals and private institutes to bring new treatments and diagnostics to market. Organizations also receive funding for prevention research, albeit to a significantly lesser degree than support earmarked for drug discovery treatment. We will address the need for additional prevention research in the “Challenges & Opportunities” section of this brief.

An IP analysis of public gifts culled from the Chronicle of Philanthropy Big Gifts Database and Philanthropy News Digest found 41 gifts or commitments exceeding \$1 million between 2020 and 2022. At 28 gifts (68%), universities were the top recipients. Examples include a \$25 million commitment from the Once Upon a Time Foundation to fund a brain research program at Peter O’Donnell Jr. Brain Institute at the University of Texas Southwestern Medical Center and a \$15 million pledge from Dan Riccio and Diane Case Riccio to support neuroscience research at the University of Massachusetts Chan Medical School.

Of the 41 gifts in our analysis, funders directed eight (20%) to hospitals and nonprofit medical clinics. In 2020, Providence Saint John’s Health Center (Santa Monica, California) received \$40 million from William and Carolyn Singleton to support the Pacific Neuroscience Institute Brain Health Center. A year later, Microsoft CEO and Executive Chairman Satya Nadella and his wife Anupama pledged \$15 million to Seattle Children’s Hospital to improve care and advance research for children with neurological conditions and brain injuries.

Funders directed the remaining five gifts (12%) to patient advocacy organizations. Examples include financial services firm Edward Jones’ \$6.5 million grant to the Alzheimer’s Association in support of research on Alzheimer’s disease and a \$20 million gift from billionaire Donald Newhouse to establish the Donald and Susan Newhouse Fund at the Association for Frontotemporal Degeneration, a form of dementia, to expand the organization’s research, education, awareness and advocacy efforts.

A separate IP analysis of Candid data on giving for brain health from 2015–2019 found that of the 10 top recipients of funding, five were patient advocacy organizations that act as regrantors – Michael J. Fox Foundation for Parkinson’s Research, Alzheimer’s Association, Alzheimer’s Drug Discovery Foundation, National Multiple Sclerosis Society and Autism Speaks. That said, it is difficult to say how much of this funding backed research as opposed to advocacy or patient care since Candid data does not break down funding by activity. The other recipient institutions in Candid’s top 10 list include the Mayo Clinic, New York University Langone Medical Center and the Kennedy Krieger Institute in Baltimore.

10 Neuroscience Research Recipients to Watch

Association for Frontotemporal Degeneration

Carnegie Mellon University

Cedars-Sinai Health System

Kennedy Krieger Institute

Mayo Clinic

New York University Langone Medical Center

Marcus Institute for Development and Learning

Stanford University

University of California, San Diego

Weill Cornell Medicine

Individual donors are more likely than private foundations to make big gifts for the creation or construction of new treatment centers, often coupling this support with funding earmarked for research purposes. Our analysis of the Chronicle of Philanthropy Big Gift database and Philanthropy News Digest identified 16 gifts or pledges providing funding for the construction of new research facilities. All but one of these 16 gifts or commitments came from an individual donor. For example, in 2020, former U.S. Congressman Herbert C. Klein made a \$5 million gift to his alma mater, Rutgers University, a portion of which established the Herbert and Jacqueline Krieger Klein Alzheimer’s and Dementia Clinical Research and Treatment Center.

Giving & Getting Deeper Dive

“Medical research” is a deceptively simple term for a field that is actually multifaceted and complex. Rather than view the term broadly, the Milken Institute’s FasterCures [lays out a continuum](#) comprising three types of research – basic or

discovery research, translational or preclinical research, and clinical research. This continuum serves as a useful organizing framework to help development officers at neuroscience research organizations get a deeper understanding of where funders are allocating support.



The National Organization for Rare Disorders (NORD) is a patient advocacy organization committed to the identification, treatment and cure of rare disorders and “orphan diseases” – defined as any condition that affects fewer than 200,000 people nationwide – through education, advocacy, research and patient services. Its Jayne Holtzer Research Grants Program provides seed grants to academic scientists for translational or clinical studies related to development of potential new diagnostics or treatments for rare diseases. Researchers can check out open grant opportunities [here](#).

Basic Research or Discovery Research. This is hypothesis-driven research focused on exploring fundamental issues regardless of the potential for practical application or commercialization. Academic research centers, government institutes and nonprofit research institutions conduct this type of research. The federal government provides the bulk of support for basic research, while pharmaceutical companies and some funders typically focus their attention on phases later in the continuum where treatments have a higher probability of commercialization.

That said, some funders focus exclusively on basic research. For example, the Los Angeles-based Kavli Foundation has endowed and supports seven Kavli

Institutes devoted to basic research in neuroscience. In 2004, it provided \$13.5 million to endow the Kavli Institute for Brain and Mind at the University of California San Diego and the Salk Institute for Biological Studies. The foundation gave the institute \$5 million in April 2022. Speaking to IP, Kavli Foundation’s Bernard said that basic research is the “underlayment for all of these other applications of either neuroscience or neurology research. There’s a very short distance to applying it to any number of different clinical areas, including Alzheimer’s and Parkinson’s disease, of course, but also things like basic cancer, so that’s where we focus a lot of our philanthropy.”

Translational or Preclinical Research. This research advances promising discoveries from the basic phase to clinical testing. Pharmaceutical companies as well as nonprofit research and academic institutions predominantly focus on translational research. According to the Milken Institute, the “full spectrum” of translational research can take three to six years on average.

An example of a gift earmarked for translational research is a \$24.5 million donation from philanthropist Rosamund Stone Zander to establish the Rosamund Stone Zander Translational Neuroscience Center at Boston Children’s Hospital to support clinical trials in translational neuroscience. Zander cited the work of the hospital’s Dr. Mustafa Sahin, who had founded the new center’s predecessor, the Translational Neuroscience Center, saying his research “opens entirely new avenues for collaboration and treatments, and in many cases, for life itself.”

The McKnight Brain Research Foundation (MBRF) is an Orlando-based funder committed to research into cognitive aging, which it defines as “a natural

process that can have both positive and negative effects, and these effects vary widely from person to person.” Trustee Madhav Thambisetty told IP that the MBRF’s grantmaking strategy “ensures that the people we fund have a clear translational focus in all the research that they do.” MBRF stakeholders also acknowledge that translational research cannot exist without fundamental basic research. As a result, Thambisetty said the foundation “tries to balance our funding portfolio to encourage basic science that has a promise of clinical translation.”

A dearth of funding or an unclear path to commercialization can prevent promising therapies from advancing to the translational stage of the continuum – a failure point known as “the Valley of Death.” The “Funder Trends and Strategies” section of this brief will look at how grantmakers aim to shepherd promising treatments through the translational research stage.

Clinical Research. This stage finds researchers testing treatments on human subjects to gauge commercial viability and safety. Early-phase trials generally include a handful of participants, while later-phase trials involve hundreds or thousands, and can last several years. Research is conducted in private research institutes, government laboratories and public and private hospitals. Donors and foundations provide robust support for clinical trials and clinical research programs. Some neuroscience research funders, like the Doris Duke Charitable Foundation, only fund clinical research. The pharmaceutical industry provides extensive support for clinical research.

Funders also support the clinical research phase by providing access to infrastructure and patient registries. The ALS Association directed \$1.4 million in clinical trial support for Amylyx

Pharmaceuticals’ Relyvrio, a drug that is designed to slow disease progression. “There’s a lot of clinical trial infrastructure we put in place, and the ALS space is small enough so that the work can happen in a fairly centralized way,” Chief Mission Officer Neil Thakur told IP.

Broadly speaking, clinical development of a single treatment takes, on average, six to seven years. Should clinical trials prove that the treatment is effective, the next step finds the drugmaker seeking FDA approval, which can take between six months and two years. The FDA’s Center for Drug Evaluation and Research approved 50 novel therapeutics in 2021, down from 53 in 2020. The five-year approval average is 51 drugs per year; 10 years ago, that figure stood at 24. It currently takes roughly 15 years and \$2.5 billion to develop and win approval for a new drug, up from \$1 billion at the turn of the 21st century.

Fundraising Spotlight



The ALS Association directed \$2.15 million in funds raised from its Ice Bucket Challenge toward the development of Relyvrio. Designed by Amylyx Pharmaceuticals, the drug is designed to slow disease progression. The ALS Association also launched an advocacy campaign making the case for the drug. The FDA approved Relyvrio in September 2022. “We’re funding a lot of infrastructure that touches more drugs,” Chief Mission Officer Neil Thakur told IP. “Relyvrio happened to be the first, but I don’t think that it’s going to be the last treatment that we’re involved with.”

The Big Issues & Beyond

Neuroscience research funders navigate a field characterized by immense complexity. While this may sound self-evident, funding leaders universally reiterated this point in our conversations.

“Understanding how the human brain works is really one of the last frontiers in science and [we want] to be able to understand it in a meaningful way to try and leverage that knowledge into tangible benefits for people and keeping them active cognitively,” said MBRF Trustee Thambisetty.

Researchers have only begun to scratch the surface of understanding the brain, further underscoring the importance of basic research and how this support can drive advancements for multiple neurological conditions. Compounding matters is that each condition has unique research demands. For example, Parkinson’s Foundation President and CEO John Lehr told IP that while “there is a much better understanding of the basic biology of Parkinson’s disease, particularly the role of the protein alpha-synuclein in disrupting cellular homeostasis and neurological death,” the field still lacks treatments that “directly inhibit alpha-synuclein’s damage in humans.”

Rather than look at the discrete research challenges for neurological conditions covered in this brief, this section will instead lay out a set of funder imperatives that can apply to the broader field. These big issues include understanding the brain’s complexity and how basic research can yield findings that can be applied to multiple fields, pursuing advancements in the biology of aging and cognitive aging, and developing diagnostic tools to enable early detection of neurological disorders. Since multiple conditions fall within the rubric of neuroscience and brain health, this section will also look at how certain illnesses lag behind others in

terms of receiving regulatory approval for treatments and philanthropic support.

Understanding the brain’s complexity.

Funding leaders consistently told IP that the largest underlying issue facing the field is understanding how the brain operates. “Our understanding of the brain continues to develop, but the field continues to grapple with basic questions of how the brain functions,” said Milken Institute Senior Director Cara Altimus. This lack of knowledge inhibits researchers’ efforts to drive advancements in basic neuroscience knowledge, but also in identifying connections across interrelated conditions.

The Milken Institute works with funders to ensure that their support accelerates progress in the medical research field. This can involve helping funders develop frameworks to identify and give grants to research organizations, direct support at key intervention points across the research continuum, and develop performance metrics to gauge the impact of their donation.

Altimus and her team encourage funders to understand that even if illnesses are “mechanically distinct, diagnosis and treatment is fluid across diseases.” For example, “since Alzheimer’s disease, Parkinson’s, ALS and more than a dozen other neurodegenerative diseases are characterized by the progressive death of neurons, breakthroughs in any one disease area are likely to drive accelerated progress in the others,” Altimus said.

CURE Epilepsy (CURE) was founded in 1998 by a small group of parents of children with epilepsy who were frustrated with the state of treatment for the condition. Since its inception, CURE has raised more than \$90 million to fund epilepsy research and has awarded over 280 grants to research

organizations in 17 countries aimed at advancing the search for a cure, eliminating treatment side effects and reversing deficits caused by frequent seizures.

CURE Chief Scientific Officer Laura Lubbers told IP that the biggest challenge facing researchers in the field is tackling the condition's multiple layers of complexity. Individuals can develop epilepsy in various ways, such as genetic mutations that start very early on in life, or through traumatic incidents to the brain, like a car accident.

"We've made a lot more headway when it comes to genetic discoveries," Lubbers told IP, "but there's still a very broad range of individuals that have epilepsy due to other causes, and finding solutions for them can be difficult." Individuals can have multiple kinds of epilepsies, such as pediatric epilepsy, post-traumatic epilepsy and sudden unexplained death in epilepsy, each of which has its own set of complex research demands. Moreover, individuals can simultaneously have multiple seizure types, further complicating efforts to

develop effective treatments. "A cure is obviously the holy grail," said CURE CEO Beth Lewin Dean. But until it's found, "there should be better data on what's going to be the most effective option for a given situation and what's the second-best choice."

The biology of aging and cognitive decline.

As people live longer, some neuroscience research funders are exploring how the natural aging process can influence or lead to the development of certain neurological conditions.

For example, it has long been understood that the No. 1 risk factor for Alzheimer's disease is aging. "But it has only been over the last few decades that researchers are digging deeper into the biology of aging to understand what happens in the aging brain that makes Alzheimer's the fifth-leading cause of death for people 65 and older," said Jane McIntosh, chief philanthropy officer of the Alzheimer's Drug Discovery Foundation (ADDF), which supports one of the largest portfolios of clinical trials across a range of drug targets informed by the biology of aging. With "new appreciation for the varied and complex mechanisms underlying this disease," McIntosh said that researchers are "now exploring an approach the ADDF has long supported – a broader drug development approach that takes 'multiple shots on goal' and targets various aspects of the biology of aging."

While 13% of people over the age of 65 develop Alzheimer's disease, a portion of the remaining 87% will struggle with cognitive decline due to the normal aging process. They may forget names, become disoriented by simple tasks, or find it difficult to manage their finances. While none of these behaviors can be attributed to a specific condition, the effects of cognitive decline will affect

Funder Spotlight



According to CURE, epilepsy affects more people than multiple sclerosis, Parkinson's, and ALS combined, but it receives less federal money per patient than each of those diseases. Established in 1998, CURE Epilepsy is the only nonprofit solely focused on finding cures for epilepsy and has awarded over \$90 million in grants toward those ends through its four grant programs. The Catalyst and Cure Epilepsy programs offer researchers 2 year, \$250,000 grants and the Taking Flight and Rare Epilepsy Partnership programs award 1 year \$100,000 grants.

millions of individuals' quality of life and exact a toll on the public healthcare system.

McKnight Brain Research Foundation (MBRF) Trustee Thambisetty is also an adjunct professor of neurology at the Johns Hopkins University School of Medicine and leads a research group working on drug discovery for Alzheimer's disease at the National Institute on Aging. He told IP that when he joined the foundation board in 2015, "the biggest challenge was, how do we define the distinction between what is normal aging and what is Alzheimer's disease?" Getting this distinction right or wrong can lead to serious consequences. Physicians would misdiagnose a patient and prescribe expensive treatments that did not address the underlying condition, or individuals would worry they had Alzheimer's when they were simply experiencing the effects of aging. This uncertainty often compels individuals to put their faith in unproven treatments or outright scams to stay mentally sharp.

Thambisetty contends that the field has made significant progress since he joined the MBRF board seven years ago. "We are now at the stage where we may have relatively noninvasive, highly accurate tests that allow us to make the distinction between who has pathology in their brain, who's likely to have Alzheimer's disease, and who may not have the telltale pathological signs of the disease," he said.

The American Federation for Aging Research (AFAR) is guided by the belief that the more researchers and physicians understand the basic biology of aging, the better equipped they'll be to delay many chronic diseases, including stroke and Alzheimer's disease, as well as cancer and diabetes. Its goal is to "establish the field of aging researchers who are looking into the biological mechanisms of

why and how we age, and how that affects the diseases of aging, including cognitive decline," said Executive Director Stephanie Lederman. AFAR funds basic and translational research and embraces the term "geroscience," which it defines as "a research paradigm based in addressing the biology of aging and biology of age-related diseases." AFAR stakeholders believe that donors will be more supportive of age-related research when they understand that the biological processes of aging are the greatest risk factors for many chronic diseases.

Research Spotlight



Established in 1981 by Irving S. Wright, AFAR supports scientists, physicians and investigators in their research focusing on the aging process and age-related diseases. AFAR has awarded \$193 million in grants to over 4,300 researchers, physicians and medical students across multiple grant programs. AFAR supporters include the McKnight Brain Research Foundation, Ambrose Monell Foundation, and Schmidt Futures.

The need for better diagnostics. Diagnostic tests and procedures help physicians confirm or rule out a neurological disorder. Common tests for neurological disorders include MRI, CT scans and an electroencephalogram. Milken Institute Senior Director Cara Altimus told IP that one of the greatest challenges for the field is developing improved diagnostic tools to "know whether and in what way the brain is not functioning well." Muscular Dystrophy Association Chief Research Officer Dr. Sharon Hesterlee echoed this sentiment, saying, "We still have a large number of people in particular disease areas, like limb-girdle muscular dystrophy, congenital muscular dystrophy and congenital myopathy, who remain undiagnosed."

In 2018, Alzheimer’s Drug Discovery Foundation (ADDF) co-founders Leonard A. Lauder, Bill Gates, Jeff Bezos and the Dolby Family announced a \$30 million research initiative called the Diagnostics Accelerator to find biomarkers – physiological measurements that provide insight into biological processes – for detection and diagnosis of Alzheimer’s and other forms of dementia.

“Biomarkers can take many forms, from the more invasive and expensive, such as PET scans and spinal fluid taps, to less-invasive and less-costly blood tests,” said McIntosh, the ADDF’s chief philanthropy officer. “Advances in biomarkers are responsible for the shift in changing the landscape and ensuring more accurate and early diagnosis using blood tests, eye scans and digital tools.”

In July 2022, the ADDF announced the second phase of its Diagnostics Accelerator, which included an additional \$50 million in commitments from philanthropic partners including the NFL Players

Association, Eli Lilly & Company, Biogen and the Shanahan Family Foundation, bringing the total amount committed to the initiative to \$100 million, including previous support from MacKenzie Scott, the Association for Frontotemporal Degeneration and the Charles and Helen Schwab Foundation. The foundation has awarded more than \$209 million to fund over 690 Alzheimer’s programs in 19 countries and supports one of the largest and most diverse clinical trial portfolios in the world, with over 30 active clinical trials.

ADDF-supported researchers are currently evaluating innovative new retinal scans and digital biomarkers, such as wearable devices and smartphone apps, that may provide a window into how Alzheimer’s disease affects the brain. “As the field develops more drugs against a wide range of targets, new biomarkers will play a larger role to give physicians the tools they need to zero in on the root causes of each patient’s Alzheimer’s and tailor combinations to provide precision personalized medicine,” said McIntosh.

Other examples of funders providing support for diagnostics include the W. M. Keck Foundation’s \$1.3 million grant to the University of California, San Diego supporting development of new investigative tools for understanding the origins of and possible therapies for neurodegenerative disorders, and a \$50 million commitment from the Atlanta-based Goizueta Foundation to establish the Goizueta Institute at Emory Brain Health Center to fuel development and application of next-generation biomarkers, among other activities.

Low FDA drug approval rates. Drugmakers in the neuroscience field often have difficulty bringing treatments to market. “It’s a pretty dismal record with regard to getting regulatory approval

Funder Spotlight



Frustrated by the slow pace of Alzheimer’s disease research, Jeff Morby, Jacqui Morby, Henry McCance and Phyllis Rappaport applied their experience in the venture capital field to launch the Cure Alzheimer’s Fund in 2004. The fund’s areas of interest include basic and translational research, drug discovery and preclinical and clinical drug development.

The fund supported University of Virginia Health researchers’ 2022 discovery of a molecule in the brain responsible for orchestrating the immune system’s responses to Alzheimer’s disease and multiple sclerosis, potentially allowing doctors to harness the body’s ability to fight those and other neurological diseases.

within a central nervous system area,” Christopher and Dana Reeve Foundation Chief Science Officer Dr. Marco Baptista told IP. “I’ve seen numbers that under 9% of programs that make it through clinical trials actually get regulatory approval.” As far as the foundation’s focus area—spinal cord injury (SCI)—is concerned, a September 2022 *Frontiers in Cellular Neuroscience* report stated that while a “large number” of clinical trials have been initiated to improve the lives of individuals with SCI, “there remain no FDA-approved treatments that can even partially improve neurological dysfunction after injury.”

Uneven philanthropic support. Experts who spoke with IP also referenced funding disparities across the broader field. “Primary brain tumors are considered a rare disease, and like many rare diseases, there is inadequate funding available to move the needle forward at a reasonable speed,” said Debbie Robbins, the director of corporate and foundation relations at the American Brain Tumor Association. Within the brain tumor research field itself, Robbins noted that “there is a significant gap in funding for brain metastases research, as most research is focused on the primary cancer.”

Some neuroscience fields have celebrity advocates committed to the cause. For over 40 years, actor Jerry Lewis hosted the Jerry Lewis Telethon to benefit the Chicago-based Muscular Dystrophy Association (MDA), which is “committed to transforming the lives of people affected by muscular dystrophy, amyotrophic lateral sclerosis (ALS) and related neuromuscular diseases. The MDA has committed more than \$1 billion to accelerate the discovery of therapies and cures since its inception in 1950 and lists open funding opportunities [on its site](#).

In 2010, the final year with Lewis as host, the MDA’s 22-hour telethon on broadcast television raised \$59 million. Ten years later, actor Kevin Hart hosted the streamed telethon during the pandemic. The event reached over 100 million viewers and raised \$10.5 million in two hours.

Other prominent funders are named after high-profile individuals afflicted with the disease or condition in question. The Michael J. Fox Foundation for Parkinson’s Research, whose namesake was diagnosed with the disease in 1998, has successfully leveraged what Forbes’ William P. Barrett called “[the power of celebrity](#)” to engage donors. The Christopher and Dana Reeve Foundation is named after the late “Superman” actor who became quadriplegic as a result of a horse riding accident.

“People are more comfortable having discussions about conditions like Parkinson’s and autism,” said CURE Epilepsy CEO Lewin Dean. “I do think having a prominent spokesperson helps.” Epilepsy doesn’t have a deep bench of high-profile advocates, even though over 3 million Americans have the condition. “Epilepsy has a particular stigma about it, and this impacts our ability to raise funds for research,” said Chief Scientific Officer Laura Lubbers.

Organizations tackling conditions that have been historically underfunded have enjoyed rapid progress in recent years thanks to an influx of philanthropic dollars. Funding from the 2014 Ice Bucket Challenge enabled the ALS Association to dramatically ramp up its giving and shepherded the FDA’s September 2022 approval of the drug Relyvrio. “We’ve gone from a long period of relatively stable treatment to a period of rapid

change, which means more people to serve, more people to train, and more payers to educate,” ALS Association Chief Mission Officer Neil Thakur told IP. “Growth brings its own challenges, and we need to be prepared, because things are moving fast.”

Similarly, the FDA has approved 12 new muscular dystrophy treatments in the last 10 years. Calling this development a “good problem to have,” Muscular Dystrophy Association Chief Research Officer Dr. Sharon Hesterlee said “the new administrative burden” and pandemic-related staffing issues have “definitely caused challenges.”

Fundraising Spotlight



AFTD’s main goal is to improve the quality of life for those impacted by frontotemporal degeneration by funding research toward diagnosis, treatment, and a cure; promoting greater public awareness of FTD; providing education for healthcare professionals and advocating for increased research. AFTD receives support from a wide range of donors including the David Geffen Foundation, Bank of America, and the David E. Reese Family Foundation.

Funder Strategies and Trends

IP surfaced three prominent, operationally oriented tactics deployed by funders to support neuroscience research organizations. First, funders adopt the principles of “venture philanthropy” to accelerate the return on high-risk, high-reward treatments. These practices inform the second strategy in which grantmakers target funding interventions to extricate a promising treatment from “the Valley of Death” and usher it into the translational stage of the research continuum.

Funders are also driving collaboration across a field replete with administrative, regulatory and funding constraints.

Venture philanthropy. “In the strictest sense, venture philanthropy connotes nonprofit organizations that invest directly in for-profit companies,” notes the Milken Institute’s FasterCures, an advisory organization that aims to lower the barriers to biomedical innovation. While the term “venture philanthropy” means a lot of things to a lot of people, it is mostly applied to situations in which a funder/investor has deep engagement with an investee (sometimes perceived as meddlesome) and provides large infusions of capital with the hope of major payoff (sometimes, but not always, in the form of profit for the donor).

“As a venture philanthropy, the Alzheimer’s Drug Discovery Foundation seeks out and invests in the most promising, high risk/high-reward science from biotech companies and academia that would go underfunded without us,” said Chief Philanthropy Officer Jane McIntosh. Parkinson’s Foundation President and CEO John Lehr defined venture philanthropy as a model in which “nonprofit organizations use donor funds to invest in promising, early-stage compounds or therapies to gather data, to demonstrate proof of concept, feasibility or safety, and to identify new pathways forward. With the development of promising treatments, pharma or biotech can then fund later and more expensive phases of clinical trials.”

In 2022, the Parkinson’s Foundation launched the Venture Philanthropy Fund to support cutting-edge research conducted by companies and nonprofits. One of the foundation’s first moves was allocating \$3 million for a strategic partnership with

Parkinson’s UK drug development arm, Virtual Biotech, to advance early-stage drug development efforts. “What I like about Virtual Biotech is how it functions like a pharmaceutical company, developing a broad range of potential therapies, some controlling the symptoms, and some really focusing on the underlying disease,” Lehr told IP after the foundation announced the fund. “The goal is to have a lot of variety.”

FasterCures ultimately finds the term “venture philanthropy” limiting as it can leave out “many disease research organizations that are taking a new, more [outcomes-driven approach](#) to philanthropy, whether or not they are investing in for-profit companies.”

Funding Interventions in “The Valley of Death.” The “Giving & Getting Deeper Dive” section mentioned “The Valley of Death”—a failure point in the neuroscience research continuum in which a lack of funding or an uncertain path to commercialization prevents a treatment from

advancing to the translational stage. Some funders seek to insert themselves at this critical juncture to move promising treatments forward.

The “Valley of Death” “is definitely something that needs to be addressed,” said the Reeve Foundation’s Baptista. “Sometimes, a gap may exist in our knowledge base, like within an academic group that’s advanced the science, and to really translate it, you’re going to need some industry expertise to help move it across the finish line.”

Writing in *Exponent Philanthropy*, [Sheri Sobrato](#), the eldest daughter of billionaire Silicon Valley real estate mogul and philanthropist John Sobrato and his wife Sue, writes that the most challenging part of the broader medical research lifecycle is “the early stage of commercialization, also known as the ‘Valley of Death.’” At this stage, Sobrato said, “the company must raise money to continue development, but the technology might still be unproven and the risks are high.” Sobrato argues that this stage of development represents an impactful intervention point for philanthropists looking to advance promising treatments.

Sobrato supports the Catalytic Impact Foundation (CIF), a nonprofit that uses funds to invest in early-stage life science and healthcare companies and guide innovative treatments through “the Valley of Death.” CIF’s portfolio includes 10 companies in its Brain Health priority area.

Boosting collaboration. Funding leaders who spoke to IP stressed the importance of building partnerships across government, academia, industry, venture capital and philanthropy. “If you collaborate, you will accomplish so much more than figuring out how to do it on your own, especially in underserved areas like cognitive aging, where

Venture Philanthropy Spotlight



Established in 2015 by its founding donor, Resonance Philanthropies, CIF makes investments in early-stage companies “to help move the most promising innovations along the path to commercialization, and through the Valley of Death.” CIF focuses on companies addressing high unmet medical need through its Women’s Health, Brain Health, Pediatric Rare Diseases, Pediatric Health, and Aging investment verticals. Its Brain Health portfolio includes companies such as Ceretype Neuromedicine and Origami Therapeutics.

there's not enough resources," said American Federation for Aging Research Executive Director Stephanie Lederman.

While the Ice Bucket Challenge provided the ALS Association with an infusion of funding in recent years, Thakur told IP there's still "not enough money in this philanthropy space to get the treatments we need, so we have to be really clear about our partnership strategy and our shepherding approach." When the association maps out its research strategy, leaders look at what the National Institutes of Health and its philanthropic partners are funding. "In a lot of cases, we collaborate and joint-fund proposals," Thakur said. "We collaborate on data archives, resource sharing – and when we're not cofunding, we're sharing notes, because that's the only way to be as efficient as possible."

Hesterlee of the Muscular Dystrophy Association (MDA) said, "One of the greatest challenges for funders now is to keep up with all of the activity across different organizations so that we aren't duplicating efforts." The MDA is partnering with two organizations focused on Charcot-Marie-Tooth disease (CMT), the CMT Association and the CMT Research Foundation, to cofund CMT research projects. "We invite one another to our meetings now to encourage these types of collaborations and I

predict we will see larger-scale efforts going forward," Hesterlee said.

Grantmakers' efforts to boost collaboration can be stymied by a culture of secrecy among competing organizations and researchers' inability to share data due to privacy regulations or technical limitations. Meanwhile, pharmaceutical companies, with a keen eye on the bottom line, are reluctant to pass along valuable intellectual property to competitors.

The Christopher and Dana Reeve Foundation is navigating this terrain by carving out what Baptista calls a "pre-competitive space" to incentivize collaboration between stakeholders, including grantseekers. Baptista told IP that he and his team are working with the Open Data Commons to identify ways to incentivize researchers to submit data to the repository. "A big push for us is to see that all the data sees the light, so we're not in a situation where people are doing work that has already been shown to not be promising because they don't have access to the data," Baptista said.

In 2018, Bill Gates convened a coalition of organizations and industry partners to form the Alzheimer's Disease Data Initiative (ADDI) to increase the sharing of dementia-related data, make

Fundraising Spotlight: ALS Ice Bucket Challenge



In the summer of 2014, the Ice Bucket Challenge went viral on social media as people all over the world dumped ice water on their heads to promote awareness of amyotrophic lateral sclerosis (ALS). Within six weeks, the ALS Association received \$115 million in donations. The challenge enabled the association to commit \$81.2 million across 275 research grants in the U.S. and \$8.5 million internationally between 2014 and 2018. Since the challenge, the National Institutes of Health invested \$415.9 million in researchers funded by the association, including \$208.6 million in follow-on funding.

it easier to share data across platforms and enable research to leverage data to develop breakthroughs. “Data sharing also helps bridge the diversity gap that is inherent in most patient datasets,” [Gates said](#). “If we can increase access to data from studies in Africa, East and South Asia, Latin and South America, or those focusing on a diverse group of participants, we can further our approach to this global disease.” Over 2,000 researchers from 80 countries currently access ADDI data.

Perspectives on Equity

This section focuses on the ways funders’ perspectives on racial and socioeconomic equity inform their grantmaking strategies. There are three key themes – the pervasive representation gaps in clinical trials for drugs that treat neurological disease, addressing the underlying economic and social issues that contribute to health disparities, and embedding equity into organizations and their grantmaking strategies.

Taking on Pervasive Representation Gaps in Clinical Trials. As discussed in the “Giving & Getting Deeper Dive” section of this brief, clinical research is one of the three components of the medical research continuum. This work finds researchers testing interventions on human volunteers to determine whether a drug can prevent or treat a neurological condition in individuals, including those with a heightened genetic risk for the disease, or if a new screening test can reduce deaths. If clinical trials lack sufficient representation from a specific racial group, researchers cannot gauge a drug’s effectiveness and safety on this demographic, leading to adverse health outcomes. “We’re not just trying to get a representative population because it’s a nice, politically correct thing to do,” said Stephanie

Monroe, executive director of African Americans Against Alzheimer’s. “Drugs will work differently in different populations.”

A 2022 Bloomberg analysis of more than 50,000 participants in drug industry and government-sponsored Alzheimer’s drug trials found that only 2% percent of patients were Black, despite the fact that 9.6% of Americans 65 and older are Black. Moreover, the Alzheimer’s Association estimates that older Black people are twice as likely to have Alzheimer’s or related dementia compared to older white individuals. Bloomberg’s analysis also found low representation of Hispanic people in trials of Parkinson’s disease drugs.

“There’s a big diversity problem across clinical trials, especially so in Alzheimer’s disease, because these trials typically require a caregiver to accompany the patient to site visits and for evaluations,” said MBRF’s Thambisetty. “And to have these visits happen over multiple times places a huge burden on underrepresented minorities, which is a tragedy in and of itself, because there’s evidence to show that many of these communities are disproportionately affected by the disease.”

Experts cite other causes for racial disparities in clinical trials for neurological drugs. “The No. 1 reason people don’t participate is they don’t know about the studies,” says Jose Luchsinger, a professor of medicine at Columbia. Other factors include researchers’ tendency to recruit individuals who have received an early diagnosis, which can prioritize affluent patients who can access preventative screening services, and what [ProPublica’s](#) Caroline Chen and Riley Wong call “the reluctance of the FDA to force drugmakers to enroll more minority patients.” Lastly, Bloomberg’s Robert Langreth and Madeline Campbell noted the

“long-standing skepticism over laboratory science and drug industry trials among some in the Black community, who point to historic abuses such as the infamous Tuskegee experiments, in which poor Black men with syphilis were left untreated.”

Inequities can also arise based on how the study is designed. A September 2022 MIT report found that most studies of autism consistently enroll small numbers of females or exclude them entirely. The authors attributed this disparity to flaws in the construction of the Autism Diagnostic Observation Schedule, a test that clinicians use to determine eligibility for the study. “The goal is that research should directly inform treatment, therapies and public perception,” said [Anila D’Mello](#), the paper’s lead author. “If the research is saying that there aren’t females with autism, or that the brain basis of autism only looks like the patterns established in males, then you’re not really helping females as much as you could be, and you’re not really getting at the truth of what the disorder might be.”

Funding leaders who spoke to IP repeatedly stressed the importance of conducting clinical trials in which the participants mirrored society’s diversity. “Conducting the best science means that you’re trying to capture as much inclusion as possible,” said Christopher and Dana Reeve Foundation’s Baptista. “So something we’re thinking about for future grants, especially if it’s a clinical trial, is making sure that the trial is being run optimally, which would mean how to best generalize a study so it applies to the entire population.”

The “Analysis of Opportunities and Challenges” section of this brief takes a closer look at how funders are working to close the representation gap in clinical trials.

Taking a Holistic Approach to Neuroscience Research. Funders are working to understand how underlying economic and social issues contribute to health disparities. This issue is particularly acute when it applies to minorities living with disabilities, a demographic that, according to a report from the U.S. Department of Health and Human Services Advisory Committee on Minority Health, faces a “double burden” that involves inadequate access to quality healthcare, disproportionate rates of mortality and other factors.

Advocacy Spotlight
UsAgainstAlzheimer's

Founded in 2010 to “disrupt and diversify the movement to cure Alzheimer’s,” this group advocates for health equity for those disproportionately affected by Alzheimer’s, including communities of color and women. Among its accomplishments, UsAgainst Alzheimer’s and its partners have secured \$10 billion in additional annual public funding for research, launched the Global Alzheimer’s Platform Foundation and created Leaders Engaged on Alzheimer’s Disease, the largest national coalition of Alzheimer’s organizations.

This is an area where funders’ research efforts overlap with issues like access to care and quality of life considerations. “For brain tumors, as they affect all races and sexes equally, this means ensuring access to the best care,” said Debbie Robins, director, corporate and foundation relations, at the American Brain Tumor Association. “For people who live in low-income or rural areas, this is extremely difficult, as the best care is often centered in academic medical centers and mature community hospitals.” Moreover, Robins said, “the financial burden is significant. Brain surgery is one of the most expensive treatments a human being can undergo.”

In August 2022, the Christopher and Dana Reeve Foundation launched two new grant programs, Racial Equity and Rural Unserved & Underserved Populations, to fund projects that provide people living with paralysis with access to healthcare, healthy food options, access to broadband and other technologies, and transportation. Foundation President and CEO Maggie Goldberg told IP that the grants are “not only about access to inpatient and outpatient care, but also addressing the challenges that these individuals face once they’re out in the world and navigating their lives.”

The “Analysis of Opportunities and Challenges” section of this brief will explore funders’ efforts to support prevention research that explores potential links between neurological conditions and behavioral, environmental and lifestyle factors.

Embedding equity across organizations.

Milken Institute Senior Director Cara Altimus told IP that she and her team found that grantmakers “benefit from improved understanding when they also consider diversity of their own team and advisors.” The institute recommends that funders look at advisory boards and the programmatic team to ensure that equity is woven into funding programs and build out research priorities in partnership with people who have a lived experience with the condition in question.

The National Multiple Sclerosis Society aims to “amplify the voices of all people affected by MS and increase the cultural awareness and professional expertise of healthcare providers and researchers.” In 2021, it [funded a grant](#) to study immune cell differences in racially and ethnically diverse populations to determine why people of specific races and ethnicities with MS tend to experience more aggressive disease.

The Parkinson’s Foundation’s Hispanic Parkinson’s Advisory Council develops strategies to increase clinical research education, awareness and participation among Spanish speakers with Parkinson’s throughout the U.S. The council’s work informs the foundation’s PD GENERation: Mapping the Future of Parkinson’s Disease, a national initiative that offers genetic testing counseling at no cost for people with Parkinson’s disease. In 2021, the foundation announced a \$10 million investment that included funding to identify people with Parkinson’s for clinical trials from historically underrepresented Hispanic and Caribbean communities.

Funders are also “promoting investment in talented scientists from diverse backgrounds,” said Parkinson’s Foundation President & CEO John L. Lehr. “This serves science well, eliminating narrow or biased research and studies.” The American Epilepsy Society’s Sergievsky Research Fund for Epilepsy Health Equity and Diversity advances the careers of doctors from underrepresented groups serving medically underserved people with epilepsy. The fund was created through a gift from the estate of Kira Sergievsky, daughter of Gertrude H. and Boris Sergievsky.



“The move toward remote and decentralized trials may actually make studies more accessible to diverse populations who faced challenges with participating in more traditional research requiring travel time, time off work and access to an institution. Identifying where there are problems and probing the causes is the first step in developing plans to reach out to underrepresented groups.”

—Sharon Hesterlee, Chief Research Office, Muscular Dystrophy Association

A Closer Look at Funder Types

The neuroscience research fundraising ecosystem is dominated by affluent individual donors, including billionaires who hail from Wall Street and Silicon Valley, as well as entrepreneurs who provide relatively smaller but nonetheless critical gifts to regional research organizations. For many of these individuals, a gift or commitment earmarked for Alzheimer's or MS research is deeply personal – they may have been diagnosed with the condition or have a loved one struggling with the illness.

Grantmaking public charities and private foundations have a relatively smaller philanthropic footprint, but are equally committed to advancing innovative research and closing funding gaps.

Corporate support mostly takes the form of donations to patient advocacy organizations that regrant it to other organizations, while community foundations channel giving through discretionary grantmaking programs and donor-advised funds.

Major Donors

As noted in the “Who’s Giving” section of this brief, it can be difficult to determine the true extent of individual giving to neuroscience research organizations because recipient institutions do not need to report gifts on Form 990s. That said, an IP analysis of the Chronicle of Philanthropy’s Big Gifts database, which, while not comprehensive, tracks gifts of \$1 million or more, and Philanthropy New Digest’s news feed, provides a revealing look into the influence of top-of-the-pyramid donors across the field.

Our analysis generated 34 gifts or commitments from donors totaling \$635 million from January

2020 to November 2022. Donors earmarked 12 grants or commitments totaling \$266 million for neuroscience research writ large. Examples include a \$25 million gift from Michael and Vikki Price to Rockefeller University to create the Price Family Center for the Social Brain, a neuroscience effort aimed at discovering the neuronal, cellular and molecular foundations of social behavior; and a \$15 million pledge from Dan Riccio and Diane Casey Riccio to support neuroscience research at the University of Massachusetts Chan Medical School.

At a total of \$204 million, donors earmarked ten gifts or commitments for Alzheimer’s research. In 2021, philanthropist Joanne Knight made an \$11.5 million gift to Washington University’s School of Medicine to prevent Alzheimer’s. In recognition of the gift and the Knight family’s history of support for Alzheimer’s research, the university named its prevention initiative the Knight Family Dominantly Inherited Alzheimer Network-Trials Unit. Our analysis also identified gifts or commitments focused on epilepsy, autism, muscular dystrophy, Parkinson’s and stuttering.

A closer look at the data finds that donors earmarked 15 gifts and commitments to create new research centers and institutes. In 2021, Frank Brunckhorst III gave Carnegie Mellon University (CMU) \$10 million, half of which was used to construct a science building that will include a new home for CMU’s Neuroscience Institute, with the remaining \$5 million supporting the institute. This gift is something of an anomaly, since most press releases do not specify how much support flows to the construction of new treatment facilities versus research. Our analysis found that the Atlanta-based Goizueta Foundation was the only private foundation to make a gift or commitment for a new research facility.

Here, we begin to see parallels with the broader higher education giving ecosystem, where alumni make huge gifts to construct new engineering buildings or athletic facilities that attract top-tier talent, catalyze economic development and boost the university's prestige. To this point, a 2019 Public Administration Review study cited the "desire to have an impact" by increasing "the quality and/or reputation" of a university as the top motivating factor behind mega-donor gifts. Other key motivations include altruism, exchange (i.e., self-interest) and leaving a legacy. Many of these large gifts for capital purposes frequently coincide with a recipient university's ambitious multiyear fundraising campaign.

Funder Spotlight

SFARI SIMONS FOUNDATION
AUTISM RESEARCH INITIATIVE

Established in 2006 as a scientific initiative of the Simons Foundation, SFARI now has a budget of around \$100 million per year. With an overall mission of improving the understanding, diagnosis and treatment of autism spectrum disorders (ASD), SFARI offers multiple grant programs to "support bold, imaginative and rigorous research." It has supported over 700 investigators in the U.S. and abroad with grants and commitments of more than \$725 million toward ASD research.

Billionaire insurance businessman Patrick Ryan and his wife Shirley's \$480 million gift in 2021 to Northwestern University encompasses these motivating forces. The couple, both of whom are alumni, earmarked the gift to construct a "best-in-class venue" to accelerate breakthroughs in biomedical, economics and business research, and propelled Northwestern's "We Will" campaign past the \$6 billion mark. "A new institute in the field of neuroscience will dramatically advance

Northwestern's distinctive scholarship in the field of neuroscience," read the [university's press release](#), before going on to note that "Northwestern Memorial Hospital ranked ninth in neurology and neurosurgery in the U.S. News & World Report 2021-22 Best Hospital rankings."

The following lists a handful of prominent major donors in the neuroscience research space that provides a representative snapshot of the giving interests in this giving area.

James and Marilyn Simons. James Simons is a mathematician, billionaire hedge fund manager and philanthropist. He and his wife Marilyn channel their giving through the Simons Foundation, which they founded in 1994. In 2006, the foundation established the Simons Foundation Autism Research Initiative (SFARI) to improve the understanding, diagnosis and treatment of autism spectrum disorders. Simons' daughter Audrey was diagnosed with autism at six years old.

In a January 2020 blog post called "[My Guiding Principles](#)," Simons wrote that he launched SFARI after he and Marilyn learned that "autism is very largely genetic; and, second, that few great scientists were working in the field." As a result, the initiative sought to "attract great scientists, and begin with genetics." Fourteen years after establishing SFARI, "not only have we discovered numerous genetic causes of the condition, but our first drug trials have been initiated," Simons wrote. SFARI has a budget of approximately \$90 million per year and supports over 300 investigators. It lists ongoing funding opportunities [on its site](#).

An IP analysis of Candid data found that the Simons Foundation gave \$99 million toward neuroscience causes from 2015 to 2019, making it the largest

funder in the data set, followed by the hedge fund billionaire Stanely Druckenmiller’s foundation (\$41 million) and the Sergey Brin Family Foundation (\$36 million). Again, it is important to note that Candid’s data set is not comprehensive, nor does its methodology determine how much funding flowed to research versus other areas like treatment or advocacy.

Sergey Brin. In 2008, Google co-founder and longtime Michael J. Fox Foundation for Parkinson’s Research (MJFF) supporter Sergey Brin said genetic testing showed that he and his mother carried the G2019S mutation of the LRRK2 gene, which is linked to rare examples of familial Parkinson’s disease. “Until the fountain of youth is discovered, all of us will have some conditions in our old age, only we don’t know what they will be,” wrote Brin in a 2011 blog post. “I have a better guess than almost anyone else for what ills may be mine, and I have decades to prepare for it.”

Two years later, Brin and his then-wife Anne Wojciki matched more than \$53 million in capacity-building gifts to the MJFF. In 2019, his Sergey Brin Family Foundation provided seed funding for Aligning Science Across Parkinson’s (ASAP), a collaborative research initiative managed by the Coalition for Aligning Science. Brin gave \$233 million to Parkinson’s research in 2021, of which \$101 million flowed to the MJFF. In 2022, he donated \$225 million toward research, including \$43 million to the MJFF.

“For context, those figures come close to the amount that the U.S. National Institutes of Health spends annually on Parkinson’s: an estimated \$263 million in the fiscal year through September 2022, and \$254 million in the prior fiscal year” wrote *Forbes*’ [Kerry Dolan](#). “The difference: Most of Brin’s

donations go toward basic research, while a significant percentage of the NIH funding goes to clinical and translational research – per its mandate.” Brin’s lifetime giving for Parkinson’s disease comes to \$1.1 billion, making him the largest funder for the disease and “one of just a few people alive today to have donated more than \$1 billion toward a specific disease,” Dolan wrote, while noting that Brin plans to launch an autism research initiative based on the ASAP model.

Initiative Spotlight

Stanford

Knight Initiative
for Brain Resilience
Wu Tsai Neurosciences Institute

With a \$75 million gift from Phil and Penny Knight, the Knight Initiative for Brain Resilience launched in April 2022. The initiative fosters increased collaboration among multiple medical and scientific disciplines. Among its many goals, are discovering what may be done to prevent, delay or reverse neurodegeneration; promoting the possibilities of brain rejuvenation and preventing and treating cognitive decline.

Phil and Penny Knight. In 2022, Stanford University announced a \$75 million gift from Nike cofounder Phil Knight and his wife, Penny, to establish the Phil and Penny Knight Initiative for Brain Resilience to explore the causes of cognitive decline from diseases such as Alzheimer’s and Parkinson’s, establish techniques to encourage healthy aging and brain resilience, and find effective treatments for brain degeneration. Phil graduated with a master’s degree in business administration from Stanford in 1962.

“As Phil and I get older, we are seeing the devastating impact of neurodegeneration on our friends and loved ones,” Penny Knight said. “We

are calling it the Initiative for Brain Resilience because we want to focus on the positive outcomes this important research may yield – healthy aging and the possibility of helping all people live fuller, more vibrant lives late into life.”

Bill Gates. As noted in this brief’s introduction, Gates announced his intention to fund Alzheimer’s research in 2017, citing the prevalence of the disease in his family as well as projected costs for care and treatment as people live longer. A year later, he joined Jeff Bezos and Leonard A. Lauder to launch the Alzheimer’s Drug Discovery Foundation’s (ADDF) Diagnostics Accelerator. In 2019, Gates partnered with the Alzheimer’s Association to launch the Part the Cloud initiative, which has gone on to raise over \$60 million for Alzheimer’s research. The following year, he helped launch the Alzheimer’s Disease Data Initiative,

Major Donor Spotlight: Arthur Blank’s Support for Stuttering Research

In 2020, Arthur Blank, the 80-year-old billionaire co-founder of Home Depot, gave a 10-year, \$20 million grant through his family foundation to establish the Arthur M. Blank Center for Stuttering Education and Research at the University of Texas at Austin. Blank is a self-proclaimed “stutterer my entire life.” In 2021, he announced a \$12.25 million grant to launch an Atlanta branch of the Blank Center, the first of several satellite locations devoted to stuttering treatment, research and training. The center will be housed at the new Arthur M. Blank Hospital, scheduled to open in 2025. The Blank Family Foundation also aims to scale programming nationally and worldwide, including Camp Dream. Speak. Live., an intensive therapy program for children who stutter.

which we discussed in the “Funder Trends and Strategies” section of this brief.

In 2021, he published a blog post titled “The Reason I Feel Optimistic About the Future of Alzheimer’s Research,” noting that ADDF’s Diagnostics Accelerator was kickstarting promising new research. “If we want to stop Alzheimer’s, one of the biggest things we need to develop is a reliable, affordable and accessible diagnostic,” he wrote. “I think we’re close to having one, and the developments we’ve seen over the past couple years make me more optimistic than ever that we can one day stop Alzheimer’s.” In July of 2022, Gates announced he would be donating \$11.25 million toward the Diagnostics Accelerator.

Hock Tan and Lisa Yang. Hock Tan is not a billionaire, but the CEO of San Jose-based Broadcom and his wife and former investment banker Lisa Yang have emerged as prominent neuroscience research funders in recent years. In 2017, the couple, who are parents of adult children on the autism spectrum, established the Tan-Yang Center for Autism Research at MIT.

Three years later, they gave \$28 million to launch the Yang-Tan Center for Molecular Therapeutics in Neuroscience at MIT to accelerate the development of novel therapies and technologies for autism and other brain disorders. The gift aligned with the couple’s strategy to fund “cutting edge research in areas that traditional funders wouldn’t fund,” Yang said. In 2021, Yang gave MIT \$24 million to create the K. Lisa Yang Center for Bionics, where scientists and engineers develop solutions to restore the functions of people affected by spinal-cord injuries, stroke, musculoskeletal disorders and other conditions caused by aging and illness.

Other major donors. Other prominent donors include Ric and Jean Edelman, a couple who made their money in finance and pledged \$25 million to fund a competition through the XPrize Foundation on finding new approaches to treating Alzheimer’s; billionaire Qualcomm co-founder Irwin Jacobs and his wife Joan, who support for the Kavli Institute for Brain and Mind at the University of California San Diego and the Salk Institute for Biological Studies; and billionaire business magnate David Geffen, who gave \$10 million to the Association for Frontotemporal Degeneration (AFTD), a form of dementia. The late Microsoft co-founder Paul Allen created the Allen Institute for Brain Science in 2003 with a commitment of \$100 million and his estate supports brain research through the Paul G. Allen Family Foundation.

Beneath the top strata of these mega-wealthy donors is a broad, deep network of affluent individuals who are not billionaires but who make gifts or commitments in the \$10 million to \$50 million range. They may not be household names, but they are the charitable backbone for most neuroscience research organizations. In 2022, philanthropist Maxine Platzer Lynn gave \$10 million to the Cedars-Sinai Health System in Los Angeles to establish the Bernard and Maxine Platzer Lynn Family Memory and Healthy Aging Program in the Department of Neurology. The program includes a brain-health program for patients at risk of developing Alzheimer’s disease.

As noted in the “Who’s Giving” section of this brief, major donors often channel support to neuroscience research organizations through donor-advised funds managed by financial services firms like Fidelity, Vanguard and Schwab, as well as community foundations. While donors will give to organizations they are familiar with, they may also

ask DAF managers to recommend organizations that may be a good fit. IP encourages leaders at neuroscience research organizations to introduce their organizations to DAF fund managers at community foundations, which are more accessible than large financial services firms. If a DAF holder asks their fund manager for advice on which cancer research organizations are doing good work, the organization might get a mention.

A closer look at the Michael J. Fox Foundation’s 2020 fundraising haul underscores the expansive footprint of major donors. Of the \$200 million the foundation raised that year, 63% came from Sergey Brin, according to *Forbes’* William Barrett. The foundation also had 113 donors who gave more than \$100,000 each.

The infusion of support from mega-donors mirrors the growing gap between top-of-the-pyramid givers and less-affluent individuals across the broader philanthropic landscape. A 2022 report from the [Institute for Policy Studies](#) found that from 2000 to 2018, the proportion of households giving to charity decreased from 66% to under 50%. In 2019, households earning \$200,000 or more accounted for 67% of all charitable deductions, with “ultra-wealthy” donors channeling support through their own private foundations and DAFs. A year later, for the first time, donations to DAFs were equal to contributions to private foundations, with both receiving roughly \$48 billion from donors.

In late 2022, the National Philanthropic Trust (NPT) [published a report](#) announcing that around 22% of charitable giving from U.S. individuals went into DAFs in 2021, surpassing the percentage for foundations, which has long hovered near 15%. Grants from DAFs to qualified charities totaled an estimated \$45.74 billion, representing a 28.2%

increase compared to 2020. NPT’s report put the average DAF account size at around \$180,000 in 2021.

These trends present two distinct challenges for fundraisers at neuroscience research organizations. First, it amplifies the importance of engaging high-net-worth donors. While development officers work diligently to engage with these individuals, many affluent donors are either inaccessible or give through opaque DAF providers. At the same time, the importance of large gifts can unwittingly deter fundraisers from engaging less affluent donors whose support can nonetheless galvanize meaningful breakthroughs. “At the heart of what we do as fundraisers is to build relationships and translate progress; this is no different in the neurological space,” said Alzheimer’s Drug Discovery Foundation Chief Philanthropy Officer Jane McIntosh. “Bringing supporters and potential supporters along with you in the narrative of optimistic progress is incredibly important.”

Donor-Named Public Charities

Under IRS guidelines, 501(c)(3) organizations are classified as either a [public charity](#) or [private foundation](#). Private foundations are usually endowed by a single benefactor, steadily distribute 5% of assets annually to other charities and do not fundraise. Public charities typically receive most of their support from the general public through fundraising activities or government sources. Sometimes, these public charities that raise funds are named for a high-profile donor, and as a result, might be confused with a private foundation. But public charities like the Michael J. Fox Foundation and the Christopher and Dana Reeve Foundation are public charities that don’t have massive endowments and must raise new funds every year.

Both private and public foundations support cutting-edge research across the continuum of types outlined in the “Deeper Dive” section of this brief, with an eye toward filling gaps in government or corporate funding. Grantseekers will find that funders’ level of accessibility varies by the institution, as some put out requests for proposals or have public applications, while others solicit proposals on an invite-only basis. Here are a handful of prominent public charities devoted to neuroscience research.



McKNIGHT BRAIN
RESEARCH FOUNDATION
Preserving memory, enhancing life

“Understanding how the human brain works is really one of the last frontiers in science and [we want] to be able to understand it in a meaningful way to try and leverage that knowledge into tangible benefits for people and keeping them active cognitively.”

—Madhav Thambisetty, trustee, McKnight Brain Foundation

Founded in 1998 after actor Michael J. Fox was diagnosed with Parkinson’s disease, the Michael J. Fox Foundation is “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.” The foundation supports clinical and translational research projects focused on therapeutic approaches and the development of promising tools to accelerate the pace of treatments. According to its Form 990 for the fiscal year ending December 2020, it had \$202 million in total revenues and disbursed approximately \$131 million in research grants, a figure that constituted 76% of total expenses. The foundation has provided more than \$1 billion in support for hundreds of high-risk, high-reward grants since its inception.

The field of spinal cord research includes two prominent donor-named charities. Founded in 1982, the Stifel Paralysis Research Foundation was renamed the Christopher and Dana Reeve Foundation in 1999 after actor Christopher Reeve, who became quadriplegic as a result of a horse-riding accident, and his wife Dana. Since 1982, the foundation has disbursed over \$140 million toward spinal cord injury research. The foundation, which has approximately \$8 million in total assets, has also disbursed over \$37 million through its Quality of Life Grants Program that fosters community engagement, improved access and independent living for individuals and families impacted by paralysis. “Our community members cannot access society because of living with paralysis,” foundation president and CEO Maggie Goldberg told IP. “It’s challenges of transportation, of work, of living in constant pain — the list goes on and on. So we see our mission as a melding of care and cure to allow people to go back to work, have families, and become active members of society.”



“Conducting the best science means that you’re trying to capture as much inclusion as possible. So something we’re thinking about for future grants, especially if it’s a clinical trial, is making sure that the trial is being run optimally, which would mean how to best generalize a study so it applies to the entire population.”

—Marco Baptista, Chief Scientific Officer, Christopher and Dana Reeve Foundation

Another key player in spinal cord injury research is the Encino, California-based Craig H. Neilsen Foundation. Launched in 2002, its namesake was an American gaming industry executive who became quadriplegic after a car accident and passed

away in 2006. The foundation has awarded \$277 million in grants, including \$126 million for spinal cord injury research on the translational spectrum and \$27 million for psychosocial research.

Other Public Charities and Intermediaries

As noted in the “Who’s Giving” section, some of the neuroscience research field’s largest patient advocacy organizations are also prominent funding intermediaries. Conversely, some large advocacy organizations have a relatively small research footprint.

The organizations listed in the subsection “Donor-Named Public Charities” would also be considered by many experts to be intermediaries.

Intermediaries in any given field gather philanthropic resources from multiple entities and make grants according to their own criteria, with widely varying levels of input from the donor entities. That is certainly true of the funders detailed in that previous subsection.

Founded in 1985, the ALS Association funds amyotrophic lateral sclerosis research and quality of life care. For the fiscal year ending January 31, 2022, it had \$91 million in net assets, \$39.8 million in total revenues and \$44.6 million in expenses. Of that latter amount, \$14.2 million — or 38% of the total — flowed to research. In 2021, the association laid out its plan to make ALS a “liveable disease” by 2030 so that anyone with ALS has access to life-extending treatments and experiences fewer physical, emotional and financial burdens. “One thing I discovered when I came into this space is that there’s a lot of energy around basic science and drug development, but other parts, like prevention or addressing the complications that come with

ASL, like the poverty and the isolation, weren't getting a lot of attention," Chief Mission Officer Neil Thakur told IP. "With a more holistic plan, we think we can get better impacts faster."

With revenues of \$377 million, the Alzheimer's Association is the self-proclaimed "largest nonprofit funder of Alzheimer's research." In 2021, the association made its largest-ever research investment, granting more than \$70 million to 253 scientific investigations. Currently, the association is investing over \$310 million in more than 950 projects in 48 countries. It lists open grant opportunities [on its site](#).

The New York City-based Autism Speaks Inc. is an autism advocacy organization and the largest autism research organization in the United States. According to Autism Speaks' Form 990 for fiscal year ending March 2021, it had \$42 million in total revenues and disbursed \$4 million in grants, most of which were earmarked for research purposes. The organization's website lists [open funding opportunities](#) and features a grants database, which shows it has awarded \$175 million since 2006.

Advocacy Spotlight



Autism Speaks advocates for increased understanding and acceptance of people with autism. Founded in 2005 by Suzanne and Bob Wright, it is now one of the world's leading organizations focused on autism science and advocacy. Autism Speaks awards grants to autism science researchers, care providers and individuals and families in need. It recently awarded \$240,000 in grants to support 54 local community providers serving autistic people with social and emotional experiences.

Autism Speaks has partnered with Google on a project called Mssng, an open-source research platform for autism that aims to become the world's largest database of sequenced genomic information of autism.

Private Foundations

As noted in the "Major Donors" section of this brief, individuals ranging from billionaires like Jim Simon and Sergey Brin to millionaire regional patrons provide philanthropic support to neuroscience research organizations through their active family foundations. Here, we will look at a handful of notable national and regional private foundations that provide similar support as part of a broader grantmaking portfolio.

Created in 2000 by Norwegian-American businessman and scientist Fred Kavli, the Los Angeles-based Kavli Foundation advances basic science in four fields – astrophysics, nanoscience, neuroscience and theoretical physics. It funds Kavli Institutes devoted to these areas around the world, awards three \$1 million Kavli Prizes annually and supports science communications work through science journalism workshops and the endowment of the AAAS Kavli Science Journalism Awards. According to the foundation's most recent [Form 990](#) for the fiscal year ending December 2020, it had \$637 million in total assets and made \$36 million in charitable disbursements. "We're trying to address and explore the gaps in terms of what we know about the fundamental human brain structure – what it's made of and how it functions – and then getting to a scientifically driven, well-clarified understanding of causative agents in disease, as well as how the brain thinks," the foundation's Bernard said.

Established in 1998, the Once Upon a Time Foundation is a \$250 million private foundation based in Fort Worth, Texas, with a strong focus on health and medicine. The foundation is one of the few funders tackling cerebellar disorders, which are problems with the cerebellum, an area of the brain that controls coordination and balance. In 2022, it launched the Raynor Cerebellum Project to improve the lives of individuals suffering from cerebellar disorders. As part of this effort, it committed \$25 million to establish the Raynor Cerebellum Project at the University of Texas Southwestern Medical Center in Dallas.

Tulsa-based William K. Warren Foundation was founded in 1945 by its namesake, the head of the Warren Petroleum Company, who passed away in 1990, and his wife Natalie. Warren's heirs preside over the foundation, which is committed to supporting medical research and care in the Tulsa region. In 2020, it established The William K. Warren Foundation Neuroscience Studies Endowment Fund at the University of Tulsa. That same year, it gave Vanderbilt University \$20 million to establish the Warren Center for Neuroscience Drug Discovery to develop viable new drug treatments with the potential to prevent brain disorders. "Supporting novel, research-based methods to combat devastating cognitive impairments and mental illnesses lies at the heart of our foundation's mission," said Warren Foundation CEO [John-Kelly Warren](#), a grandson of the founders.

The Los Angeles-based W. M. Keck Foundation was established in 1954 by the late W. M. Keck, founder of the Superior Oil Company. Its priorities include medical research, science and engineering, and undergraduate education. It has disbursed \$832 million in research grants to over 250 recipient

institutions since its inception. It established the W. M. Keck Center for Collaborative Neuroscience at Rutgers University to bring effective treatments to people with spinal cord injury and awarded grants to neuroscience researchers at Brandeis University, University of California-Davis and UC-San Diego between 2020 and 2022. Grants are typically \$2 million or less. The foundation lists upcoming grant opportunities [on its site](#).

The New York City-based JPB Foundation, created by Barbara Picower in 2011, has focus areas that include environmental issues, poverty and medical research. The foundation supports a Parkinson's disease consortium, which supports scientists at the Massachusetts Institute of Technology's Picower Institute for Learning and Memory who are exploring the brain's capacity for memory and studying the diseases that contribute to neurological dysfunctions. According to its Form 990-PF for the fiscal year ending December 2019, JPB had \$212 million in total revenues and disbursed \$9 million to organizations across all of its interest areas, including grants to support research into Alzheimer's and Parkinson's disease, dementia and children's brain health. IP's analysis of Candid data found that the grantmaker gave \$18 million toward neuroscience-related causes between 2015 and 2019, although the data set does not specify funding for research purposes.

In 1991, investor Richard Rainwater established the Fort Worth-based Rainwater Charitable Foundation to improve the lives of children in the United States, specifically targeting those born into poverty. In 2009, it launched the Tau Consortium with the goal of supporting institutions focused on accelerating the development of new treatments for Alzheimer's disease, frontotemporal dementias and other neurodegenerative diseases involving the

tau protein. When he passed away in 2015, Rainwater left nearly all of his estate for charitable purposes, primarily through his foundation.

Three years later, the foundation established the Rainwater Prize Program for new treatments for neurodegenerative diseases related to the accumulation of tau protein. Since launching the Tau Consortium, the Rainwater Charitable Foundation has invested \$100 million in tau research, accounting for roughly 65% of all U.S. philanthropic funding for tau-related research, including 75% of all U.S. philanthropic funding for treatment development.

Collaborative Research Spotlight



Managed and funded by the Rainwater Charitable Foundation, the Tau Consortium works to “establish and foster collaborative networks that seek to improve our understanding of tauopathies and develop effective treatments for patients.” The consortium has partnered with the Michael J. Fox Research Foundation to create the PIPETTE Consortium, CurePSP to form the Prime of Life Brain Initiative, and the Alzheimer’s Association to create the Tau Pipeline Enabling Program.

Corporate Funders

Corporate philanthropy for neuroscience research primarily takes the form of donations to patient advocacy organizations, collaborative partnerships that lack a financial component. Corporate funders typically approach philanthropy from a different vantage point than institutional grantmakers, community foundations and individual donors. “A lot of corporations have questions about ‘what do you have in terms of programs that I can put my

name and logo on now?’ And that’s just different than a private foundation,” Ben Cameron, Jerome Foundation president and former manager of community relations at Target, [told IP in 2021](#). “A private foundation isn’t looking for market share. Corporations, though, have a bottom-line responsibility to shareholders.”

IP research suggests that, on the whole, corporations do not establish and manage in-house grant programs. One rare example is the LEGO Foundation, which in 2022, announced the launch of a \$20 million accelerator grant program in support of innovative, play-based learning for neurodivergent children.

Rather than build out grantmaking programs from scratch, corporations provide charitable donations to patient advocacy organizations, which, in turn, can regrant the funds to researchers. Corporate donors to the Muscular Dystrophy Association include CITGO (\$5 million+ annually), the grocery company Albertsons (\$1 million+), and 7-11 and Jiffy Lube (\$500k to \$1 million). The Epilepsy Foundation lists Allstate, the Cleveland Browns and biotech company Biogen as “Strategic Partners” that have committed \$5,000 to \$24,999 toward research. Autism Speaks’ corporate supporters include Panera Bread, The Home Depot and the Wilson Sporting Goods Company.

The Alzheimer’s Association provides an instructive look into how a patient advocacy organization partners with corporations in a charitable and non-financial capacity. The [organization’s site](#) lists “Visionary Partners” (CVS Health, Marshalls and the financial services firm Edward Jones, which has pledged to raise \$50 million over 10 years to support the association), “Accelerator Partners” (AmazonSmile and OnStar)

and “Catalyst Partners” like Procter and Gamble, which partnered with the association to create a Home Safety Checklist to help families and caregivers keep their loved ones living with dementia safe.

The association received approximately \$2.4 million in donations from 17 pharmaceutical companies including Genentech, Eli Lilly and Company, AbbVie Inc., and Johnson & Johnson in FY21. This support accounted for less than 1% of the association’s total contributed revenue.

The Parkinson’s Foundation’s website lists nine “corporate sponsors” from the pharmaceutical field, including Abbott and Acadia Pharmaceuticals, although it’s important to remember that “sponsorships” are distinct from philanthropic giving. According to the [Partnership Group](#), sponsorships are essentially business transactions in which the sponsor pays or gives the organization money in exchange for something “that will help them make more money, be it through alignment with the property,” or through sales, brand development, public relations or employee engagement.

Crowdfunding charitable gifts has become an increasingly common strategy among corporate funders looking to support nonprofits while strengthening their brand. Engage for Good’s 2019 study, “America’s Charity Checkout Champions,” found that charity checkout campaigns raised more than \$486 million in 2018. Some critics question the effectiveness and transparency of these programs. Speaking to IP in 2022, [Lucy Bernholz](#), a senior research scholar at Stanford University’s Center on Philanthropy and Civil Society, said, “At the same time that philanthropy is talking about ‘outcomes’ and ‘impact’ and being able to trace your

dollar to the number of lives saved, there’s this boom in this highly intermediated, completely opaque process of giving money to CVS or Safeway.”

Bernholz has been unable to determine how much money companies raise through customer crowdsourcing or how much flows to the intended charity. “What probably happens is that a company sets a budget for how much money they’re going to give to a charity and they raise that money off the backs of customers, and when they hit their preset number, they give it,” Bernholz said. “And as for the rest of it – who the hell knows?”

Initiative Spotlight


The LEGO Foundation

Launched in 2022, the Play for All Accelerator is providing funding for up to 25 social ventures creating products and services for neurodivergent children. The initiative focuses on early-stage and EdTech organizations focusing their work on neurodiversity in general and ASD and ADHD specifically. Play for All is awarding up to \$20,000 to the 25 organizations selected to participate in the Engage phase and 12 of those groups are eligible for a grant of up to \$1 million to participate in the Accelerate phase.

Community Foundations

Community foundations support neuroscience research organizations through discretionary grantmaking and donor-advised funds (DAF), which constitute the majority of funding.

The New York Community Trust, which had \$3.5 billion in total assets as of 2021, provides discretionary grants for neuroscience research organizations. Irfan Hasan, the trust’s deputy vice president for grants, told IP that the common

theme across its discretionary medical research grantmaking is “to help early and mid-career researchers start projects and gather data needed to apply for larger government or private grants and to primarily support research projects for cancer, heart disease and incurable diseases, which covers our work in Alzheimer’s and Parkinson’s.”

The trust also directly supports patient advocacy organizations. Recipients include the Alzheimer’s Association, Parkinson’s Foundation, Michael J. Fox Foundation for Parkinson’s Research, the Brain & Behavior Research Foundation, the Muscular Dystrophy Association and the Amyotrophic Lateral Sclerosis Association.

When it comes to DAF giving, the trust’s DAF manager connects the donor with the philanthropic advisory department. Based on the donor’s goals and needs, the advisor provides “a simple list of vetted organizations, complete with their mission, programs, financial health and contact information,” Hasan said. Trust staff also introduce donors to nonprofit executives, arrange site visits, and facilitate meetings between donors and grantees in its offices.

Other community foundations that manage DAFs take a similar approach. As previously noted in the “Major Donors” section of this brief, IP advises fundraisers to reach out to their local community foundations to introduce the organization to DAF managers and discuss discretionary funding opportunities or potential partnerships.

With \$11 billion in total assets, the Silicon Valley Community Foundation (SVCF) is the country’s largest community foundation. A review of publicly available information suggests it does not provide significant discretionary support to neuroscience research organizations.

In April 2020, approximately \$10 billion of the SVCF’s total assets sat in DAFs. A review of the foundation’s Form 990 for the tax year ending December 2019 shows that donors provided support to the Alzheimer’s Association (\$668,850), Pacific Stroke Association (\$111,414), Michael J. Fox Foundation (\$95,550), National Multiple Sclerosis Society (\$43,150), Society for Neuro-Oncology (\$15,000) and the National Council on Severe Autism (\$10,000). (Like all DAF managers, the foundation is not required to disclose donor names or report grants under \$5,000.)

Similarly, a search of the Chicago Community Trust’s database of discretionary grants did not generate any support for neuroscience research. However, an analysis of the trust’s Form 990 for the fiscal year ending September 2020 revealed donor-advised grants to the Alzheimer’s Association (\$130,817), Brain Research Foundation (\$61,703), the Kirk Gibson Foundation for Parkinson’s (\$50,000), Els for Autism Foundation (\$50,000), Parkinson’s Foundation (\$28,500) and the Michael J. Fox Foundation (\$11,750).

Intiative Spotlight



The Alzheimer’s Drug Discovery Foundation’s Diagnostics Accelerator is challenging researchers to develop novel approaches toward the discovery of cutting edge biomarkers and diagnostic technologies that will aid in the diagnosis and clinical trial design of Alzheimer’s disease. The accelerator was launched in 2018 with \$100 million in total commitments from Bill Gates, Leonard Lauder, the NFL Players Association, Mackenzie Scott, and many others.

Intermediaries and Associations

Funders also join forces with grantmakers and organizations to address gaps in research. The scope and complexion of co-funding opportunities varies based on many factors, including the neurological condition in question.

This paper has addressed two of the space's most prominent funding collaboratives, which, not coincidentally, focus on the well-resourced fields of Alzheimer's and Parkinson's disease. The first, which we discussed in the "Big Issues and Beyond" section, is the Alzheimer's Drug Discovery Foundation's (ADDF) Diagnostics Accelerator. The ADDF calls the accelerator "the only public charity solely focused on accelerating the development of drugs to prevent and treat Alzheimer's, employing a venture philanthropy model to support research in academia and the biotech industry." The ADDF lists the accelerator's open funding opportunities [on its site](#).

The "Major Donors" section noted that the Sergey Brin Family Foundation provided seed funding for Aligning Science Across Parkinson's (ASAP), a collaborative research initiative managed by the Coalition for Aligning Science. The partnership, which was incubated at the Milken Institute, leveraged the Michael J. Fox Foundation's grantmaking and scientific infrastructure to process proposals, issue grants and support scientific teams. In October 2021, ASAP announced grants totaling \$132 million over three years in support of collaborative research to better understand the underlying causes of Parkinson's disease. "Altogether, the ASAP Initiative is backing 35 research teams in 14 countries supported by \$290 million in funding," wrote Forbes' Kerry Dolan in December, 2022. "And the effort will

likely continue for the rest of this decade." [ASAP's site](#) lists funding opportunities.

Muscular Dystrophy Association's Hesterlee told IP that while "there are not a lot of big collaborative funds in this area, there are many small, cooperative funding opportunities." For example, organizations frequently participate in cofunding a collective request for application (RFA) that may fund one or more grants. MDA launched a collective RFA with Parent Project Muscular Dystrophy and Cure Duchenne. (Duchenne muscular dystrophy is a genetic disorder characterized by the progressive loss of muscle.) "We probably need more collaborative funds, but they can be very tricky to administer," Hesterlee said, citing challenges in harmonizing data across partners' disparate data management systems.

In the brain tumor research field, the Sontag Foundation, James S. McDonnell Foundation and American Brain Tumor Association funded the Brain Tumor Funders' Collaborative. The [collaborative's site](#) does not list any current funding opportunities as of December 2022. The Healthy Brains Global Initiative launched in 2021 to advance brain science breakthroughs. Supporters include its primary funder, Bank of America, as well as Johnson & Johnson and the Wellcome Trust. However, the initiative's website does not list current funding opportunities, and its [most recent news item](#) dates back to October 2021.

One organization that operates somewhat like an association, the Milken Institute's [FasterCures](#), is dedicated to lowering the barriers to medical innovation and helping funders maximize their philanthropic impact. FasterCures does not provide funding, and while its primary audience consists of executives at medical research foundations,

development officers can leverage these findings to engage donors more effectively. FasterCures provides white papers, podcasts, videos with medical experts and policy issue briefs like “A Call to Action for Diversity in Clinical Trials.”

FasterCures is also home to a handful of affinity networks composed of leaders at medical research foundations. One such group, the [Research Acceleration and Improvement Network](#), consists of foundations interested in the venture philanthropy approach to medical research.

IP encourages development officers to connect with brain-health-related giving circles by contacting their local community foundation or searching Giving Compass’ [Giving Circle Directory](#).



American
Brain Tumor
Association®

“Primary brain tumors are considered a rare disease, and like many rare diseases, there is inadequate funding available to move the needle forward at a reasonable speed. There is a significant gap in funding for brain metastases research, as most research is focused on the primary cancer”

—Debbie Robbins, the director of corporate and foundation relations, American Brain Tumor Association

An Analysis of Opportunities & Challenges

IP analysis suggests that neuroscience research organizations and funders will need to implement new and innovative ways to educate donors about the importance of basic research, which remains an underfunded stage of the neuroscience research continuum. At the same time, professionals across the field are calling on philanthropy to expand on its efforts to promote data sharing, close representation gaps in clinical trials and ramp up support for prevention research.

Making the Case for Basic Research. The “Deeper Dive” section explored basic research as the fundamental component of the neuroscience research continuum. Basic or foundational research helps organizations make progress given “the absence of a clear understanding of brain function,” says Altimus of the Milken Institute. And yet, Altimus notes, “it can be particularly hard to drive interest in foundational research” given donors’ desire to accelerate breakthroughs for immediate commercial use.

CURE Epilepsy Senior Director, Marketing and Communications Debby Hecht told IP that she sometimes sees what she called an “I want it now!” mentality among some donors who expect their support to generate immediate breakthroughs. “But basic science is the backbone, and if you have that, you’re not going to get the cure,” she said.

As a result, foundations, recipient organizations and patient advocacy organizations are devising ways to better make the case for basic research. Hecht and her team work with researchers to craft impact stories to show funders that their donation for basic research led to a measurable outcome.

“We’re coming up on 25 years, and we’re now in the position to say, ‘It’s been years in the making, but look what it’s allowing us to do,’” Hecht said. “We are selling hope, but we want hope to translate into something real. So we have to make people understand that with their support, hope becomes tangible.”

“Funders naturally want results,” said Lehr of the Parkinson’s Foundation. “Negative results should not be viewed as failures, as researchers often learn as much from failures as successes.” Lehr encourages his fellow grantmakers to “take the long view and remain committed despite adversity. Sustained funding is critical as it ensures a stable research environment.”

Jane McIntosh, the Alzheimer’s Drug Discovery Foundation’s chief philanthropy officer, shared similar sentiments. “With highly publicized ups and downs over the past decade in Alzheimer’s research, there can be the perception that the science is slow-moving,” she said. “Making the case and telling the story to potential donors can be a challenge, but also an opportunity to inspire. There is much optimism about today’s robust and diverse pipeline as the field moves into a modern era, not only in the range of its drug targets, but in the ability to implement more rigorous clinical trials that track and determine the relationship between biomarker and clinical outcomes.”

Galvanizing Data Sharing and Harmonization. Technological advances over the past 20 years have generated an endless torrent of data. Yet parts of the neuroscience field lack standardized governance mechanisms to ensure

that researchers can safely share and access this data. “Who fills that gap of making sure a researcher in France can compare their data with, say, somebody in Australia?” asked the Kavli Foundation’s Bernard.

The answer could lay with private philanthropy, and experts told IP that grantmakers should double down on this approach. One of the Kavli Foundation’s programs within its neuroscience priority area is Open Data in Neuroscience, which aims to create “mechanisms to leverage vast quantities of data generated by neuroscientists and to fuel novel discoveries through open data.” In March 2022, the foundation provided [seed funding](#) to Associate Professor Franco Pestilli at the University of Texas at Austin to develop an International Data Governance Framework. The foundation hopes the project will lead to the development of a more robust infrastructure of policies and connect researchers. “There’s a lot of untapped potential here,” Bernard said. “It’s a challenge and an opportunity to incentivize researchers to collaborate and get the good science you need to understand the varieties of the brain.”

Project Spotlight

Parent Project Muscular Dystrophy

Since it was established in 1994, PPMD has invested \$50 million “in every single therapeutic possibility for Duchenne.” PPMD’s advocacy work has also led to 40 pharmaceutical companies investing \$8 billion in Duchenne and the federal government investing over \$600 million in this space. The average lifespan of someone with Duchenne has increased by 10 years as a result of PPMD-led advances in Duchenne care.

CURE Epilepsy Chief Scientific Officer Laura Lubbers told IP that the harmonization of disparate health records “could be a rich source of information to help guide us on treatments, especially for early life epilepsies where families are looking at a lifelong journey.” To this point, CURE is prioritizing the development of “common data elements” for specific epilepsies to allow researchers to access standardized data across the spectrum of research. This work could yield treatments that would effectively put an end to doctors’ current scattershot approach to treating patients with multiple seizure types.

In the neuromuscular disease field, Muscular Dystrophy Association’s Hesterlee told IP, “If there isn’t an infrastructure to do rigorous data collection in a consistent, global way, then companies are left to develop these databases themselves in ways that are duplicative, expensive and ultimately produce data silos.” Hesterlee said several nonprofit organizations in the space that maintain large clinical databases, including the MDA, are in discussions about combining efforts to produce a publicly available data source for this purpose.

Expanding Participation in Clinical Trials.

The “Perspectives on Equity” section of this brief looked at why demographics are underrepresented in clinical trials for neurological treatments. This inability or reluctance to participate in clinical trials frequently transcends racial or ethnic lines. In a November 2022 poll of 1,000 people aged 50 to 64 conducted by the University of Michigan Institute for Health Care Policy and Innovation, only 12% of respondents said they would be “very likely” to participate in a trial testing a new dementia drug. Respondents cited the amount of time it would take, the expectation that dementia would not

affect them, and “concerns over being a ‘guinea pig’ or the potential harm,” said the study’s author [Chelsea Cox](#). Health experts predict dementia cases in the U.S. will double by 2050.

“Donors should prioritize seeking out and investing in diverse, multidisciplinary research teams, working to ensure clinical trials are inclusive and treatments are affordable,” said the Milken Institute’s Altimus. To achieve this aim, grantmakers are pulling from a post-pandemic playbook that includes embracing decentralized trials and telemedicine to minimize the burden of participation and expand the number of recruits, and build partnerships to educate community members about the importance of clinical trials.

The pandemic forced clinicians to adopt remote data collection since individuals couldn’t participate in in-person trials. As the technology continues to mature, Hesterlee said that “the move toward remote and decentralized trials may actually make studies more accessible to diverse populations who faced challenges with participating in more traditional research requiring travel time, time off work and access to an institution.” MDA actively monitors the participant diversity at sites via its neuroMuscular ObserVational Research (MOVR) [clinical database](#). “Identifying where there are problems and probing the causes is the first step in developing plans to reach out to underrepresented groups,” Hesterlee said. For example, if the data suggests that people aren’t able to take time off work during standard clinic hours, MDA stakeholders can work with its partners to pilot alternate hours at different sites.

McKnight Brain Research Foundation Trustee Madhav Thambisetty told IP his team is setting up an initiative that leverages telemedicine to

diversify its pool of recruits for clinical trials. In such a scenario, patients could undergo a memory test at home or send saliva samples through the mail. “All of these advances in decentralizing clinical trials would help diversity trials,” he said.

We previously cited Jose Luchsinger, a professor of medicine at Columbia, who said that the No. 1 reason people don’t participate in neurological clinical studies is that they aren’t aware of them. Luchsinger led a trial whose enrollment was one of the most diverse examined by Bloomberg, [with almost one-third](#) of the participants identifying themselves as Black. To attract patients, Luchsinger visited local senior centers, community organizations and churches in neighborhoods around the university, including Harlem, to talk about mild cognitive impairment and tell people about the trial. Columbia offered free car service to the university, including appointments on weekends for patients who couldn’t take time off from work or cared for grandchildren during the week.

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“As long as philanthropy remains focused upon filling the leaks in the dam of society and supporting the functioning of systems that were created to extract, concentrate and diminish life, they will fail to rise to the opportunities of this era where the very foundations upon which our modern civilization has been built have been laid bare. Philanthropy should become emboldened to lead at the edges of what is possible, not constrained by what it feels is right or limited to filling the gaps and unmet needs left behind by a society functioning, as it was intended to.”

—Foundation professional, Santa Fe, New Mexico

With locations in San Antonio and the Rio Grande Valley, the Alzheimer’s Disease Research Center’s staff members go door-to-door to educate mostly Hispanic residents about available resources and clinical trials. The center also takes a holistic approach toward research, exploring how factors like environmental pollutants, the fabric of neighborhoods, and vascular disease can influence how the disease affects its Hispanic constituency. “If we bring diversity, not just check the box, but include the experiences of these people, we’ll have a better chance of understanding what’s affecting memory,” said [Gladys Maestre](#), the center’s co-director.

Research Spotlight



The Milken Institute Center for the Future of Aging “elevates awareness, advances solutions, and catalyzes action to promote healthy longevity and financial wellness.” The center’s Alliance to Improve Dementia Care is a multi-sector effort focusing on detection, access to treatment, coordinated care and health equity for people at risk of dementia. According to Milken, if the onset of dementia can be delayed by five years, it could reduce the incidence of diseases that cause dementia by 50%.

Funding leaders who spoke with IP encourage organizations to adopt similar practices to educate historically underrepresented demographics about the importance of clinical trials. “If we’re looking to diversify clinical trials, education is extremely important,” said Lederman of the American Federation for Aging Research. “It’s important to go into the community and tell people why we’re doing the trial and how it will affect people and their families.”

While there’s an enormous amount of work to do, some funding experts cited causes for optimism. McIntosh of the Alzheimer’s Drug Discovery Foundation (ADDF) referenced the [Bio-Hermes study](#), a “first-of-its-kind, head-to-head study” comparing leading biomarkers for detecting Alzheimer’s, which enrolled 24% of study volunteers from traditionally underrepresented communities, “substantially surpassing the diversity of most Alzheimer’s clinical trials.” The ADDF is a scientific partner in the effort.

Boosting Investment in Prevention Research.

While grantmakers primarily direct funding toward diagnostics and shepherding groundbreaking treatments to market, they are also adopting a more holistic approach to preventative research. “There is a growing awareness that connections between the brain and the rest of our bodies are critical,” said the Milken Institute’s Altimus. “Scientists are increasingly focusing on immune function, metabolic health, sleep and circadian rhythms, and physiological stress as areas of greater need, but also increased complexity.”

In a similar vein, [Julie Collens](#), a board member of the Alzheimer’s Association’s San Diego/Imperial chapter, noted that “there’s significant investment in understanding other behavioral and lifestyle factors that can prevent disease, and understanding variation in the development of disease in people from different backgrounds. This disease [Alzheimer’s] is complex, and it’s being tackled from all possible angles.”

IP identified three areas where research can move the needle in the field of prevention research – identifying links between neurological conditions and behavioral and lifestyle factors, COVID-19, and manmade changes to the climate.

In one of many examples in which researchers are exploring links between lifestyle and specific conditions, in 2022, researchers discovered that people who work in manufacturing, welding and chemical operations and are exposed to hazardous chemicals may face a higher risk of developing amyotrophic lateral sclerosis (ALS). “We have known for some time that certain pollutants can increase ALS risk, but identifying where these exposures are occurring is important as we begin to think about strategies for ALS prevention and studying populations of individuals at high disease risk,” said the study’s co-author, Dr. Stephen Goutman, director of the Pranger ALS Clinic.

Researchers are only beginning to understand potential links between COVID-19 and certain neurological diseases. A 2022 Case Western University School of Medicine study published in the *Journal of Alzheimer’s Disease* found that Americans over the age of 65 who had COVID-19 ran a greater risk of receiving a new diagnosis of Alzheimer’s disease within a year. In a previous study, the same researchers discovered that patients with dementia had a significantly higher risk for COVID-19 than patients without dementia. While some experts cautioned that more research needed to be conducted, the study and those like it represent a promising funding area for grantmakers.

Another growing area of opportunity involves correlations between climate change and neurological conditions. A 2022 report published in the American Academy of Neurology’s medical journal *Neurology* found that extreme weather events accelerated by climate change are associated with an increase in strokes, migraines and seizures, an increase in hospital visits among patients with

dementia and worsening severity of multiple sclerosis symptoms.

Kavli Foundation’s Bernard told IP the foundation will be rolling out a new focus area, Neurobiology and Changing Ecosystems, exploring how anthropogenic (e.g., man-made) changes to the climate influence neurons and circuits of the brain. The term “changing ecosystems” includes climate change, but also habitat degradation, noise and light pollution, and microplastic proliferation. Bernard said the foundation will publish a review paper toward the end of 2022 providing an overview of the field and making the case for philanthropic support to better equip researchers to predict how neuronal systems may adapt to future changes.

“We want to start asking questions to determine if changes are happening at a fundamental neurobiological framework level,” Bernard said. “As a grantmaker, we’re focusing on pulling together researchers from disparate fields to get them to think about those questions. Then, we’ll see whether we can set a direction for the field and can pay things forward with funding.”

Resources

Reports & Data Sets:

[Getting Started: The Medical Research and Development Primer.](#) (2017). The Milken Institute

[Measuring and Improving Impact: A Toolkit for Nonprofit Funders of Medical Research.](#) (December 2021). FasterCures

Sobrato, S. (March 8, 2022). [Using Venture Philanthropy To Fill Gaps and Advance Medical Breakthroughs.](#) Exponent Philanthropy

[The 2022 DAF Report.](#) (2022). National Philanthropic Trust

[The Outsized Impact of Philanthropy on Biomedical Research.](#) (September 23, 2020). The Milken Institute

Websites & Individual Pages with Key Information

[Alzheimer's Researchers Highlight the Need for Inclusive Clinical Trials.](#) (September 30, 2022). News-Medical.Net.

Bahr, B. (January 17, 2022). [Blank Donates \\$12M For Atlanta Stuttering Center.](#) *Atlanta Jewish Times.*

Barrett, W. (December 26, 2021). [Michael J. Fox's Foundation Debuts Among Nation's Top 100 Charities.](#) *Forbes.*

Bushard, B. (November 16, 2022). [ALS, Dementia And Strokes Worsened By Climate Change, Researchers Find.](#) *Forbes.*

Chen, C. & Wong, R. (September 19, 2018). [Black Patients Miss Out On Promising Cancer Drugs.](#) ProPublica.

Collens, J. (November 2, 2022). [Opinion: The State of Alzheimer's Research Has Changed Remarkably – and For the Better.](#) *San Diego Tribune.*

Dolan, K. (December 9, 2022). [Google Cofounder Sergey Brin Has Quietly Donated More Than \\$1 Billion Toward Parkinson's Disease.](#) *Forbes.*

Langreth, R. & Campbell, M. (April 19, 2022). [Alzheimer's Trials Exclude Black Patients at 'Astonishing' Rate.](#) Bloomberg.

[Leonard A. Lauder, Bill Gates and Jeff Bezos Joined by New Partners in \\$100M Global Research Effort to Answer Urgent Need for Early Detection of Alzheimer's Disease.](#) (July 26, 2022). Alzheimer's Drug Discovery Foundation.

McFarling, U.L. (September 28, 2022). [On the Texas-Mexico Border, a Bold Plan to Diversify Alzheimer's Research Takes Shape.](#) Stat.

Mullard, A. (January 4, 2022). [2021 FDA Approvals.](#) Nature.

Murez, C. (November 4, 2022). [Clinical Trials Could Help Stop Alzheimer's. But Who Will Join Them?](#) U.S. News.

Trafton, A. (September 17, 2022). [MIT Researchers Say Autism Studies Tend To Exclude Women.](#) SciTech Daily.

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Feedback?

The State of American Philanthropy is an ongoing project. Each SAP brief will be updated periodically to integrate new information, additional data and evolving perspectives. This brief was originally posted to Inside Philanthropy in February 2023. If you have comments or information you'd like to share with us, please email us at managingeditor@insidephilanthropy.com.