


RYAN GARCIA FOR THE CHRONICLE

# How Nonprofits Helped Fuel the Opioid Crisis

**Drugmakers donated tens of millions of dollars to patient-advocacy and physicians' groups. Those organizations helped create a massive market for deadly painkillers.**

By JIM RENDON

INVESTIGATION

Penney Cowan was fed up. She had visited doctor after doctor for her debilitating pain, but no one could help. It took six years for her fibromyalgia to be diagnosed. She felt alone, misunderstood, and unable to advocate for herself. After completing a program to help her understand and manage her pain at the Cleveland Clinic, she realized many others were suffering just like she was. Sitting at the kitchen table with her husband in 1980, she started what was likely the first advocacy group for pain patients in the United States — the American Chronic Pain Association.

"Pain is so isolating. I felt like I was the only person in the world," she says. "My mission has been, for the last 40 years, to look for that one person out there who believes there's no hope and that nobody cares. I want to let them know that I care and there is hope."

Cowan and her husband volunteered. There were few funding sources for a nonprofit like hers. An occasional grant, like a small one in 1982, helped with printing materials. Another in 1995 from the Mayday Fund, a foundation dedicated

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to alleviating pain, allowed Cowan to hire her first part-time employee. In 1997, the American Chronic Pain Association had only $81,000 in donations. Cowan still remembers the first time the nonprofit ended the year with $300 in the bank: "We thought we were doing really well," she says.

Today almost 8,000 patient-advocacy nonprofits represent people with an array of illnesses. The vast majority of them are tiny operations — like Cowan's was — with budgets totaling tens of thousands of dollars, according to a study led by a researcher at the Cleveland Clinic. But Cowan's charity didn't stay tiny. It grew fast over the past 20 years. At its peak, in 2014, it had total revenue of almost $800,000 — making it much larger than most patient-advocacy organizations.

Cowan's influence grew as well.

She founded national Pain Awareness Month. She has served on committees at the U.S. Food and Drug Administration and Centers for Disease Control and Prevention. She has presented to the World Health Organization and the United Nations and has visited 80 Veterans Administration hospitals to talk about pain. Her organization has support groups all around the United States.

**The relationships between opioid makers and nonprofits raise questions about whether organizations can withstand the pressure and potential conflicts of interest that come with such financing.**

Cowan was able to rise from her kitchen-table beginnings to her high-profile role as an advocate for those with pain today due in large part to one key factor: Pain has become big business. And pharmaceutical companies saw nonprofits like Cowan's as a key to their growth.

A *Chronicle* investigation has found that patient-advocacy groups, physicians' organizations, and other nonprofits became an integral part of the pharmaceutical industry's efforts to sway doctors, patients, and policy makers to create broad new markets for opioids. These relationships show how corporate money can manipulate nonprofits and raise questions about whether organizations can withstand the pressure and potential conflicts of interest that come with such financing, particularly when it is undisclosed.

The damage from prescription opioids has been wrenching. Communities have been destroyed by addiction, and 247,000 Americans died from prescription-opioid overdoses from 1999 to 2019. There have been thousands of lawsuits, government committees have conducted investigations, and a few pharmaceutical executives have gone to prison. Yet most patient-advocacy groups and other nonprofits involved in the crisis have failed to grapple meaningfully with their role and the vulnerabilities the crisis has exposed.

Former U.S. Senator Claire McCaskill, who was the senior Democrat on the Homeland Security and Governmental Affairs Committee, which put out a 2018 report on nonprofits and opioid manufacturers, said there's plenty of blame to go around. Pharmaceutical companies, physicians, and even the Drug Enforcement Administration are among the parties culpable in the country's opioid crisis. But nonprofits played a special role.

"It was a false narrative pushed by the opioid industry, facilitated by these not-for-profits," McCaskill says. "I'm pretty cynical. Even I was surprised by the lengths these organizations were going to protect the opioid industry."

## Drive to Expand the Market

At the end of 1995, the U.S. Food and Drug Administration approved Purdue Pharma's OxyContin, a powerful time-release opioid painkiller. Other strong opioids were approved in the ensuing years. At the time, doctors hesitated to prescribe opioids outside of end-of-life care because they were concerned about addiction, says Andrew Kolodny, co-director of opioid policy research at the Heller School for Social Policy and Management at Brandeis University and an expert witness for states and cities suing opioid manufacturers.

Purdue realized that terminal cancer patients represented a small market. Kolodny says the company wanted to persuade doctors to prescribe OxyContin to a much larger potential pool of customers: patients with acute and chronic pain.

To that end, Purdue and other opioid manufacturers began trying to persuade doctors to change the way they assessed the dangers of opioids and how they treated pain. "What they were really doing was sponsoring this campaign to change the culture of prescribing, to make doctors feel more comfortable with opioids as a class of drug," Kolodny says.

Pouring money into nonprofits was one of the key ways companies sought to boost opioid prescriptions and sales.

Over the course of two decades, opioid manufacturers awarded more than $60 million to nonprofit organizations, according to a 2020 Senate Finance Committee investigation, gaining influence with and access to patient advocates and physicians' groups that could be credible messengers for the manufacturers' business strategy, according to government investigations and internal documents made public as a result of lawsuits.

The American Chronic Pain Association's revenue growth was tied directly to donations from opioid manufacturers. In 2014, the group's best year financially, funding from these companies accounted for 90 percent of its revenue, according to the 2020 Senate report and its informational tax returns.

In the past, information promoted by opioid manufacturers could be seen in the guides the group produced and distributed to doctors, pharmacists, and patients. Some older versions of the guides reviewed by the *Chronicle,* particularly those from a decade or more ago, downplay the risk of addiction to prescription opioids, present scientifically questionable information that could lead to increased prescribing of opioids, and emphasize the risks of over-the-counter painkillers. These same arguments appear in publications

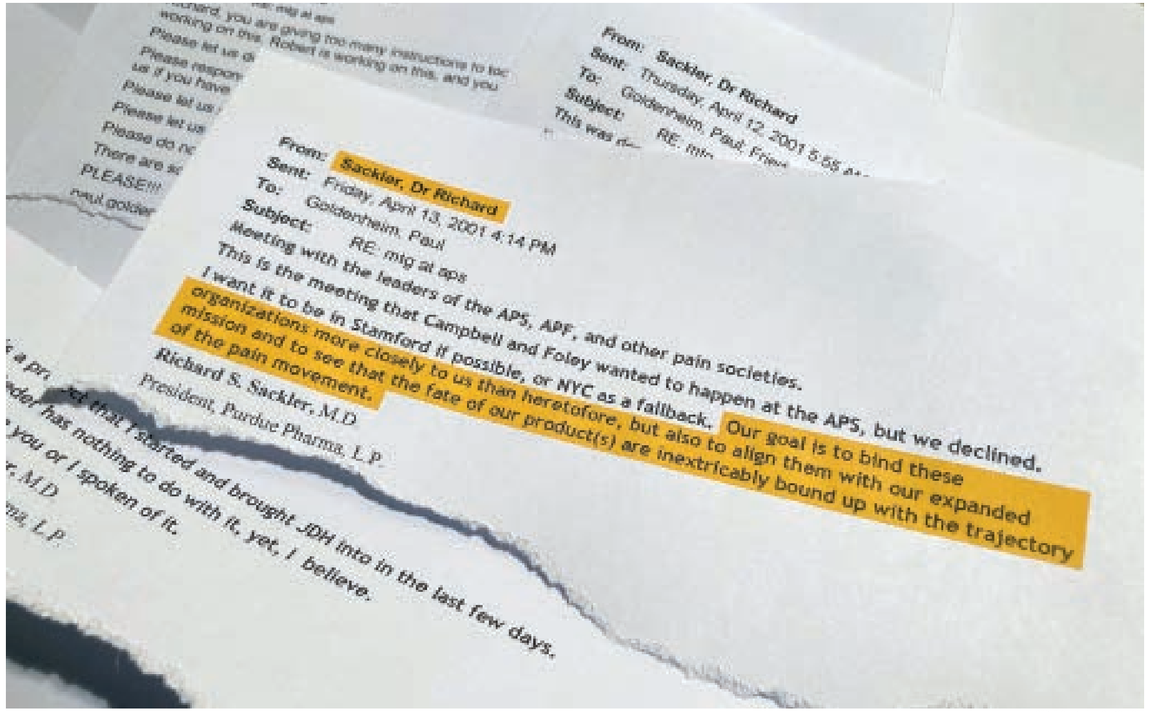


ILLUSTRATION BY THE CHRONICLE

from other groups that also received funding from opioid manufacturers.

Cowan says the guides emphasize the need for an individualized approach to pain management, and she always advocates for a balanced approach and never promotes particular drugs.

While patient-advocacy groups and their leaders may view themselves as independent actors with their own missions and agendas that sometimes line up with those of pharmaceutical companies, opioid manufacturers saw things differently. They saw nonprofits as instrumental to achieving the business goal of boosting prescriptions and sales of opioids. Internal documents disclosed in lawsuits describe nonprofits as "partners" and refer to them in company business-strategy plans.

Richard Sackler, the former president and co-chairman of Purdue, spelled it out succinctly in a 2001 email when he wrote to the company's medical director regarding a meeting he wanted with several nonprofits. "Our goal is to bind these organizations more closely to us than heretofore but also to align them with our expanded mission and to see that the fate of our product(s) are inextricably bound up with the trajectory of the pain movement."

A spokesperson for the Sackler family did not respond to a request for comment.

In a written statement, a spokeswoman for Purdue did not address the information in this article but instead wrote that the company plans to appeal a recent district court decision overturning a bankruptcy court plan to allow Purdue to become a public-benefit company and that would shield the Sacklers from future lawsuits in exchange for $4.5 billion from the family. The company, she wrote, will also continue to try to create consensus on a plan that would provide funds to communities affected by the opioid crisis.

## Fifth Vital Sign

Nonprofits helped pave the way for the opioid crisis from its beginning.

In 1995, the year OxyContin was approved by the FDA, James Campbell, then the president of the American Pain Society, a nonprofit physicians' group that received more than $15 million over two decades from opioid manufacturers, called for pain to become the fifth vital sign. The idea was to get the nonprofit Joint Commission on Accreditation of Healthcare Organizations, which accredits health care facilities, to require hospitals to assess and treat pain in every patient just as they do abnormal blood pressure or trouble breathing. Such a shift could turn opioids from niche medicines into drugs prescribed hundreds of millions of times a year.

A 1997 grant from the Robert Wood Johnson Foundation, one of the country's largest and most respected health care grant makers, helped bring that vision to life.

The foundation's $1.6 million grant to the University of Wisconsin's medical school enabled staff there to push the Joint Commission to require doctors in hospitals to assess pain in every patient. The medical school staff working on the grant drafted the language for the policy change, put together the research, and made presentations to various committees within the Joint Commission. They even helped present the changes to the board of commissioners, which approved them, according to grant reports released in the multidistrict lawsuits against the opioid manufacturers.

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**CLEAR GOAL**
**Pharmaceutical companies saw nonprofits as instrumental to boosting prescriptions and sales of opioids, as Richard Sackler, the former president of Purdue Pharma, explained in a 2001 email.**

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In 2001, pain became the fifth vital sign, just as the American Pain Society envisioned.

The foundation's director at the time, Steven Schroeder, who is now a professor of health and health care at the University of California at San Francisco, says this grant was in reaction to a foundation-funded study that showed that many people were suffering debilitating pain at the end of their lives. At the time, many other medical organizations were also seeking ways to alleviate suffering at the end of life. Indeed, Schroeder's grant approval letter said that the grant was "to establish standards for the assessment and treatment of pain in the terminally ill."

But the grant correspondence shows that end-of-life care was only part of the goal. The grant proposal said that the project's purpose was to improve pain management "in the terminally ill and in those who experience pain from surgery or trauma as well as those who suffer from cancer or chronic non-cancer pain. We believe that everyone regardless of diagnosis should expect and receive appropriate pain management." One grant report says that the Joint Commission supported standards for end-of-life pain, but not pain in all patients. The grantee credits foundation staff for helping her develop a strategy to overcome that opposition.

> "I'm pretty cynical. Even I was surprised by the lengths these organizations were going to protect the opioid industry."

When the Robert Wood Johnson Foundation made that grant, about 65 percent of its endowment was invested in Johnson & Johnson stock — it was founded with company stock and has been divesting over time. Five recently retired company executives served as foundation trustees. And Johnson & Johnson had a growing opioid business that would eventually bring in billions of dollars a year.

Schroeder says conflicts of interest between the foundation and Johnson & Johnson were inevitable because they both work in health care. But, he says, the board only ratified the grant-making recommendations of its staff — there was no conspiracy among trustees to pump up the company's profits. At the time, no one could have anticipated the opioid crisis, Schroeder says.

Jordan Reese, a spokesman for the foundation, said in a statement that it develops programs without regard to any company in which it is invested, has diversified its endowment, and is a completely separate entity from Johnson & Johnson. He said the foundation has clear conflict-of-interest policies for its staff and trustees and that this grant did not create a conflict of interest. The resulting standards did not require the use of drugs to manage pain. He added that the foundation is very concerned about the opioid crisis and is working with others to advance policies and practices to prevent another such crisis.

In a written statement, a spokesman for Johnson & Johnson, said the Robert Wood Johnson Foundation is an independent institution, and it is "unaffiliated" with any business decision of Johnson & Johnson.

In a written statement, a spokeswoman for the University of Wisconsin did not answer questions but instead said that the medical school grantee had done work focusing on the assessment and management of cancer pain and had received funding from the Robert Wood Johnson Foundation to develop recommendations for the Joint Commission on pain assessment and management standards.

The year the standards went into effect — 2001— marked an inflection point for opioid prescribing. Nationwide, prescription opioid sales increased fourfold from 1999 to 2008, with the vast majority of the increase occurring after 2001, according to a CDC study. And deaths from prescription opioids jumped fivefold from 1999 till the peak in 2016.

Physicians were under pressure to treat pain and to prescribe opioids after the Joint Commission rules changed, says Anna Lembke, medical director of addiction medicine at Stanford University School of Medicine, an expert witness in cases against opioid manufacturers, and author of *Drug Dealer MD,* about the opioid crisis. The Joint Commission's decision to make pain the fifth vital sign played a big role, she says.

A spokeswoman for the Joint Commission said that the group did not comment on subjects related to pending lawsuits.

Over the next two decades, opioid manufacturers pumped tens of millions into nonprofits — some groups received as much as $6 million each from 2012 to 2019. With that influx of money, nonprofits targeted pain patients, pharmacists, and physicians with messages that pushed the idea that pain was a vast and undertreated problem, opioid pain medicines were relatively safe and effective, addiction risk was low, and other pain medications posed health risks, according to documents released in lawsuits by states and cities and investigations by Congress and others.

## Secretive Relationships

Groups that advocate for pain patients and policies are not the only ones that receive corporate support from businesses that can profit from their work. Patient-advocacy organizations of all kinds routinely take money from pharmaceutical companies and medical-device manufacturers.

A 2017 study of 104 large patient-advocacy groups published in the *New England Journal of Medicine* found that 83 percent of them took donations from industry sources. It also shows how ill-prepared nonprofits can be for the pressures and conflicts inherent in such funding. Just over 10 percent of groups had published institutional conflict-of-interest policies. Because organizations don't have to disclose the source of any of their funds, members, policymakers, and the public are rarely aware of the pharmaceutical companies' influence.

"Industry payments to patient groups are ubiquitous, often pretty substantial, and rarely fully transparent," says the study's author, Matthew McCoy, an assistant professor of medical ethics and health policy at the Perelman School of Medicine at the University of Pennsylvania.

The opioid crisis, however, has exposed these once-secretive relationships. Thanks to investigations by congressional committees and details revealed in lawsuits against opioid manufacturers, the murky intersection between the nonprofit world and pharmaceutical companies intent on using the credibility of patient-advocacy, policy, and physicians' groups to boost their bottom line is visible. And it provides insight into larger challenges patient-advocacy groups and other nonprofits face.

"Doctors responded to this brilliant marketing campaign disguised as education, and the prescribing took off. It led to a public-health catastrophe," Kolodny says. "We would not have had an opioid addiction epidemic were it not for the role played by nonprofits."

## Industry Money

Over the years, the "partners and contributors" section of the American Chronic Pain Association's website has read like a court docket of companies that have been sued over the opioid crisis. The logos of Purdue Pharma, Janssen, Teva Pharmaceuticals, Endo International, and other companies accused of wrongdoing have made appearances on the association's site, along with other benefactors.

The group Cowan founded is not unusual in taking these funds — the study by Cleveland Clinic researchers found that two-thirds of patient-advocacy groups accepted industry funding. It stands out only because she is so meticulous about disclosing the sources of her nonprofit's financing.

While patient groups say that funding does not influence their decisions or policies, opioid lawsuits show pharmaceutical companies that provided the funding were intent on gaining influence.

A 2011 internal Janssen document, called a "Pain Brief Advocacy & Policy Monthly," released in Oklahoma's lawsuit against Johnson & Johnson, lists the group Cowan founded under the heading "Primary external partner."

In a company presentation — "Update & 2013 National Advocacy Business Planning" — nonprofits are referred to as partners, and the company writes that it is looking to "support good pain policy." It includes a flow chart that begins with an "advocacy vision" of "mobilizing partners to advocate for policies that insure [sic] adequate access to pain care." Its "Advocacy Strategy" includes helping patients "improve access." Cowan is mentioned as part of the Imagine the Possibilities Pain Coalition and as the author of a paper the group was preparing. When the paper was published, she was not an author but was thanked for reviewing it. Nine of the coalition's 19 members were Janssen employees.

The Janssen presentation, which details the company's relationships with and expectations for advocacy groups, mentions Cowan's group several times. That same presentation includes a chart of "Proposed National Advocacy Activities," on which the American Chronic Pain Association and 16 other nonprofits and associations are marked for both "policy" and "access."

In a statement, a spokesman for Johnson & Johnson, which owns Janssen, said the company's marketing and promotion of opioids as well as its "funding of independent studies, physician education, and advocacy organizations on both the benefits and risks of these medicines were appropriate and responsible." And the company did not coordinate its promotional activities with other companies. He said the Imagine the Possibilities Pain Coalition met four times and produced one peer-reviewed study of the military's pain-management work with returning veterans.

Cowan says the American Chronic Pain Association has refused donations because she will not mention particular products or brands. The group's board, however, was worried about the high level of funding from pharmaceutical companies, according to minutes of an October 2011 board meeting obtained through a public-records request. "Concerns arose that the appearance of bias may harm the mission of the organization," the minutes said. Board members recommended reaching out to pharmacies and health insurers for funding.

Cowan says she never knew the reasoning behind the corporate support for her group, just that it allowed her organization to produce publications that helped people in pain — and did not influence the content of the materials. She says the materials never named specific drugs and that she would have loved to get support from other sources, but it was scarce.

"I have written grant [proposals] to so many foundations," she says. "I don't just write them to pharma companies. I've written them to every big and small foundation, and I don't get anything." Advocating for pain patients, she says, is just not an issue that most foundations want to fund.

"I can sleep at night because of the way we've done things," she says. "Every nonprofit out there gets money from pharmaceutical companies."

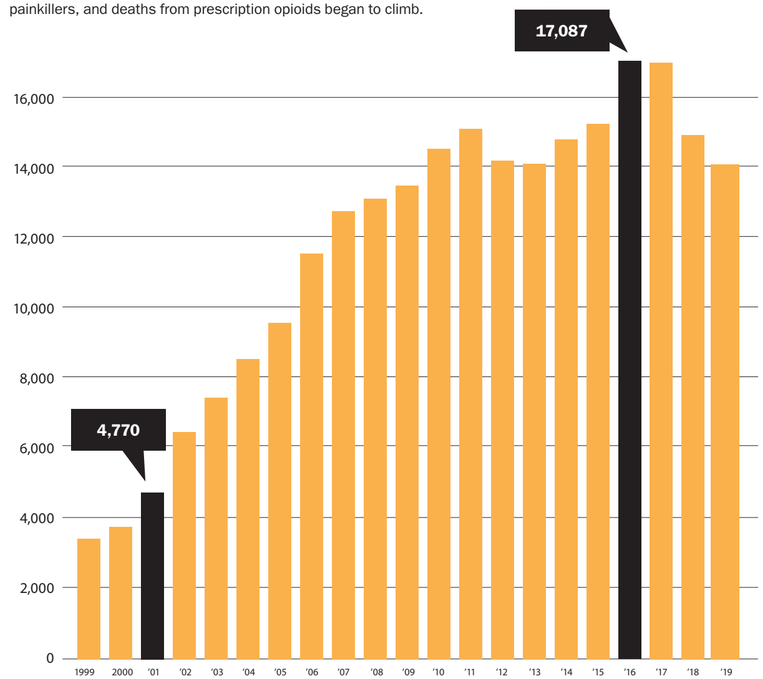
## 'Sackcloth and Ashes'

While it is rare, a few patient-advocacy groups

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### Prescription Opioid Deaths

After the Joint Commission, a nonprofit that accredits health-care facilities, changed its guidelines in 2001 to require hospitals to assess pain in every patient, experts say doctors were under pressure to prescribe painkillers, and deaths from prescription opioids began to climb.




Source: Centers for Disease Control and Prevention




CAROLYN KASTER, AP

**FOLLOW THE MONEY**
**Former U.S. Senator Claire McCaskill was the senior Democrat on the Homeland Security and Governmental Affairs Committee, which put out a 2018 report that documented payments from drug makers to patient-advocacy groups and physicians' organizations.**

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do shun money from pharmaceutical companies and device manufacturers.

The National Women's Health Network, a women's health advocacy and education group, refuses all industry funding, even from vitamin companies.

Cynthia Pearson, the network's former executive director, says other women's health organizations question the group's decision not to take the money.

"I have the impression sometimes that they think we are a little bit nuts — not in our policy decisions but like we are wearing sackcloth and ashes," she told the *Chronicle* before she stepped down last year. In 2020, the group had revenue of about $1.5 million. "We pay a big price at a cost to ourselves and our ability to work."

In 1978, the network's board decided that taking industry money would compromise its ability to be a trusted source of information about women's health. About 17 percent of the group's funding comes from members — membership starts at $15 — and about 40 percent from foundations. The organization has never been as prominent as it could be if it were better funded, Pearson says.

But the tradeoff has been worth it, she says. Pearson says other nonprofits have made policy decisions that benefit their industry supporters even though they're not based on the best science. During a short period when the FDA required people testifying at hearings to state their funding sources, she saw speaker after speaker disclose funding from manufacturers whose products they were advocating for. In the Cleveland Clinic study of small patient-advocacy groups, 8 percent said they felt pressure to conform their views to those of corporate donors.

Those pressures and conflicts have been clear to Andy Betts, CEO of the PKD Foundation, a group that advocates for people with a once-fatal kidney disease. The first drug to treat the condition was approved in 2018, and more are in the pipeline. The group receives very little money from the medical industry — an average of 3 percent of its revenue over the past five years. But Betts expects to see growing interest from industry as more drugs become available. The group publishes its donor policies and discloses corporate support. But Betts has grown cautious as a result of the conflicts exposed by the opioid crisis.

"We're treading carefully in that space because we've seen other nonprofits that have gone too fast," he says. "We've got 40 years of trust with patients, and the last thing we want to do is put ourselves in a situation that creates any kind of jeopardy to that trust. We take that very seriously."

Industry relationships can be insidious for small groups that often lack rigorous policies, legal resources, and sophisticated board members, Pearson says. "We're all humans," she says. "We do grow to like and understand the perspectives of the people we spend time with."

But Marc Boutin, the former CEO of the National Health Council, a century-old trade association for patient-advocacy organizations, sees things differently.

Relationships with industry, whether they are financial or through board members or advisers, are crucial for patient-advocacy groups. They help nonprofits better understand issues pharmaceutical companies face, such as drug development, insurance-company policies, and pressure from hospitals and device manufacturers.

"There are times when the interest of the patient community and the industry are aligned," he said before leaving his position. "We're very aligned on driving innovation and getting better treatments and even cures. We're not aligned on some of the issues around pricing."

Rather than shun industry, he says, nonprofits should ensure diversity in their funding. If they receive money from competing interests, no one point of view will dominate.

Among the group's 38 standards for its members is a requirement to disclose every corporate contribution. Corporate donors must also guarantee the recipient's independence in its decision making.

Many groups do not meet those standards, Boutin says. Of the estimated 7,800 patient-advocacy groups, about 65 — less than 1 percent — are members, although the rigorous standards may not be why they don't join.

## Conflicted Advisers

Even with funding from pharmaceutical companies and device manufacturers, many patient-advocacy organizations still operate on tight budgets. Yet they often need to develop policies and materials about complex medical topics that require expertise. Most rely on volunteer advisers who help the nonprofits understand and act on complex topics without spending a fortune on consultants. But some of those people, even those with sterling reputations, can have deep conflicts of interest that often go undisclosed. And they can use their advisory roles to shape the policies of these groups, the materials they produce, and even which ones grant makers choose to fund.

Medical advisers have played an important role for Cowan's American Chronic Pain Association. In 2007, the association received funding from Purdue to produce a tool kit for pharmacists. The publication, which was published by Partners for Understanding Pain, made up of more than 80 groups and led by the Chronic Pain Association, discussed the risks of liver damage, gastric bleeding, and kidney failure from over-the-counter pain medicines like Advil and Tylenol, while downplaying the risk of addiction to opioids.

"It is extremely rare for a person to become addicted to drugs given for acute pain, unless there was pre-existing addiction or abuse," one section reads.

The assertion lacks a source but was common in publications put out by nonprofits backed by opioid prescribers. A one-paragraph letter to the editor from 1980 in the *New England Journal of Medicine* that asserted that addiction among hospital patients receiving opioids was rare is the best-known source for this idea. Although it was a brief letter and not a peer-reviewed study, it has been cited more than 600 times and now includes an editor's note that says the letter has been "'heavily and uncritically cited' as evidence that addiction is rare with opioid therapy."

By 2007, when the tool kit was published, some studies had begun to show that addiction was a problem. One study assessing research on the medical use of opioids on back pain going back to the 1960s found that "aberrant medication-taking behaviors occur in up to 24 percent of cases." Another from 2005 found that OxyContin abuse was "prevalent" in the United States.

The tool kit was published just months after three Purdue executives and the company pleaded guilty to misleading regulators, doctors, and patients about the addictive nature of OxyContin, resulting in a $600 million fine.

Cowan says the group's medical materials were written by the chairman of its advisory board and reviewed by its members. That advisory board included experts with ties to opioid manufacturers and groups that received funding from them. Its chairman is Dennis Turk, director of a research division in the Department of Anesthesiology and Pain Medicine at the University of Washington School of Medicine and part of the department's research division.

Turk is a former president, treasurer, and board member of the American Pain Society, the nonprofit physicians' group that pioneered the idea of pain as the fifth vital sign. It disbanded in 2019 after being named in multiple lawsuits over the opioid crisis. It received $15.1 million from three opioid manufacturers from 1997 to 2018, according to data in a 2020 U.S. Senate report. The Pain Society produced educational materials and guidelines and financed the distribution of booklets for physicians that promoted increased opioid prescribing and downplayed the risk of addiction.

Gail Scott, a graduate researcher at the University of the Sciences in Philadelphia and a former Purdue sales representative, says she had these booklets to give to physicians, as did many other sales representatives. "You're trying to educate

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physicians, and it does appear more credible to give them something from a third party," she says.

The American Pain Society has been described as a key partner in the pharmaceutical industry's effort to increase opioid sales in lawsuits against the opioid manufacturers and in McCaskill's investigation.

David Haddox, a dentist who worked for Purdue for nearly 20 years, was another adviser to the American Chronic Pain Association. He originated the term pseudoaddiction: the unsubstantiated idea that patients who show clear signs of addiction are not, in fact, addicted.

Instead, according to his theory, those patients are best treated by increasing their doses of opioid pain medicine. That course of action would, in fact, exacerbate their addiction, potentially leading to complications or death, according to Andrew Chambers, an associate professor of psychiatry at the Indiana School of Medicine who treats patients with addiction. Haddox published a case study of a single patient that he said was pseudoaddicted to opioid painkillers. No other studies ever validated the term, and it has never been an official medical diagnosis, according to Chambers, who co-wrote a study identifying the origin of the term and debunking its validity.

Maryland's lawsuit against opioid manufacturers said the term "wholly lacked scientific evidence" but was one common way companies promoted their products.

"Pseudoaddiction is not a validated construct," says Stanford's Lembke. "There's no science behind it." Yet, she says, this idea, which was pushed by opioid manufacturers and the nonprofits they funded, allowed doctors and patients to be in denial about prescription opioid addiction and to continue prescribing and taking the drugs.

The term was commonly used in publications put out by nonprofits funded by opioid manufacturers, including the 2007 tool kit and other guides created and distributed by Cowan's group through 2014.

Haddox no longer works for Purdue. His consulting firm, which contracted with Purdue in 2019, has no website or phone number, and he could not be reached through Purdue for comment.

According to the McCaskill report, advisers to Cowan's group received more than $140,000 from opioid manufacturers from 2013 to 2017.

Cowan says she knew little about her medical advisers. She says they were all chosen by Turk, the director of the advisory board. "We didn't vet them in any way," Cowan says.

In a written statement, a spokeswoman from the University of Washington School of Medicine says that Turk is not a medical doctor but is an expert in nonmedical treatments for individuals with chronic pain. The statement says Turk recommended board members to Cowan's group based on their expertise and background and that Cowan and the Board of Directors made final decisions. The spokeswoman says Turk was not aware of anyone's ties to pharmaceutical companies.

The National Health Council requires that people serving on the boards of its member groups disclose possible conflicts of interest. It does not, however, prohibit industry representatives from serving on those boards. Boutin, the council's former CEO, argues that pharmaceutical officials can offer valuable and diverse perspectives. But even the National Health Council, which holds its members to stringent standards, does not have guidelines on whether or how to assess advisers' potential conflicts of interest.

## Not a One-Off

Of course, medical advisers are not the only ones whose influence is cloaked in secrecy. While foundations must disclose what nonprofits they give money to, corporations do not. And nonprofits don't have to disclose the identity of their donors to the public. Opioid manufacturers took advantage of this lack of transparency to advance their commercial goals behind the cloak of credibility provided by nonprofits. Advocates say that requiring greater disclosure would go a long way toward restoring trust in patient-advocacy groups after the opioid crisis.

> **"We've got 40 years of trust with patients, and the last thing we want to do is put ourselves in a situation that creates any kind of jeopardy to that trust."**

Before she lost her re-election bid in 2018, McCaskill introduced legislation that would have expanded a 2010 sunshine law to require pharmaceutical companies to disclose funding to patient-advocacy and education groups, physicians' organizations, and others. The legislation went nowhere. After publishing the report on opioid manufacturers in 2020, then-Senate Finance committee chairman Chuck Grassley and then-ranking committee member Ron Wyden recommended that pharmaceutical companies and medical-device manufacturers be required to report payments to tax-exempt groups through the Centers for Medicare and Medicaid Services Open Payments database. But that has not happened.

The deep-seated problems of pharmaceutical companies using nonprofits to advance their agenda have not disappeared with the attention to the opioid crisis. They have simply moved along to the next phase of that epidemic, says Scott, the former Purdue sales representative turned academic.

She is now researching companies that develop and market drugs to help treat addiction. There have already been a handful of publicized cases of treatment groups accepting money from the pharmaceutical industry association and a company that makes an implant for an anti-addiction drug. She says some companies that make these drugs are funding patient-advocacy groups just like Purdue, Janssen, and other opioid manufacturers did when they set off the opioid crisis. The model is the same — fund the nonprofits so the profit-boosting message is credible — only the issue has shifted.

"Wherever there is money, there are going to be people who want to twist and distort the nonprofit sector and bend it to their will — without the public realizing that they are the ones pushing the agenda of that particular nonprofit," McCaskill says. "I don't think this is a one-off in the opioid area. I am positive there are other organizations out there that are being manipulated the same way."

For links to the documents discussed in this article, read the online version at

**philanthropy.com/opioids**