CASE STUDY

Organizing Patients to Advance New York's Campaign to End Medical Debt

COMMUNITY CATALYST

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Organizing Patients to Advance New York's Campaign to End Medical Debt

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COMMUNITY CATALYST and THE COMMUNITY SERVICE SOCIETY OF NEW YORK

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Introduction

THANKS TO THE AFFORDABLE CARE ACT (ACA), more Americans than ever before have access to quality affordable health coverage. But despite the impressive coverage achievements secured by the ACA, the U.S. Consumer Financial Protection Bureau has determined that over half (58 percent) of all collection actions are for medical debt.[1]

There are two phenomena fueling the increased attention to medical debt actions brought against patients by their medical providers. First, insurance products—whether obtained through employment or on the Marketplace—are increasingly shifting costs onto their enrollees through deductibles and increased cost-sharing.[2] Second, the hospital industry claims that it is experiencing thinner margins and is thus forced to turn to collections agents in what patients and advocates perceive to be an ill-conceived effort to boost their margins back up.[3]

Like much of the rest of the country, New York has witnessed a historic decline in its uninsurance rate, from 10 percent to 4 percent since the ACA's enactment. But simultaneously, we have witnessed an increase in consumer complaints related to aggressive medical collection actions. For example, Community Health Advocates, New York's Independent Consumer Assistance Program reports seeing a 64 percent increase in medical debt cases over the past two years.[4]

The following case study describes the campaign consumer advocates in New York are waging to elevate consumers' concerns about aggressive medical debt actions and to reform medical debt laws in New York. New York's medical debt agenda includes a long list of reforms and has a complex legislative history, but to date three major reforms have enacted:

1. Cutting the length of time a hospital has to sue a patient from six years to three years;
2. Reducing the amount of judgment interest that can be charged when a hospital sues a patient from 9 percent to 2 percent; and
3. Closing a loophole in the Surprise Bill law that exempted hospital emergency rooms.

This brief describes how we did it, what we still need to do and the lessons we have learned along the way.

THE CAMPAIGN PLAN

The Health Care for All New York coalition (HCFANY.org) is a robust statewide coalition of more than 170 advocacy and consumer groups that joined together to fight for affordable quality coverage for all New Yorkers in 2008. Past successful HCFANY campaigns include: securing a universal children's health insurance program that covers children regardless of immigration status; the adoption of a Basic Health Plan (called the Essential Plan) that provides free,

1 Consumer Financial Protection Bureau, "Market Snapshot: Third-Party Debt Collections Tradeline Reporting," July 2019 available at: https://files.consumerfinance.gov/f/documents/201907_cfpb_third-party-debt-collections_report.pdf

2 Sara C. Collins, David C. Radley, and Jesse C. Baumgartner, "State Trends in Employer Premiums and Deductibles, 2010-2019," The Commonwealth Fund, November 20, 2020, https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/state-trends-employer-premiums-deductibles-2010-2019.

3 Emily Glee, "The High Price of Hospital Care," Center for American Progress, 2019, https://www.americanprogress.org/issues/healthcare/reports/2019/06/26/471464/high-price-hospital-care/

4 Data from Community Service Society of NY. Unpublished source.

no deductible coverage to over 900,000 New Yorkers up to 200 percent of the federal poverty level; the first-in-the-nation Surprise Bill law, which serves as a model for the newly enacted federal No Surprises Law; young adult coverage up to the age of 29; a robust insurance rate review process; and the establishment of a state-based insurance Marketplace that seamlessly provides enrollment into public and ACA insurance, including Emergency Medicaid for undocumented immigrants who are otherwise ineligible for coverage.

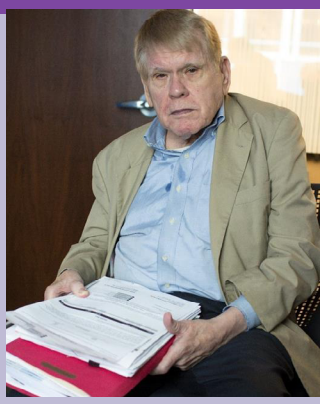
HCFANY advocates have long leveraged the six organizing capacities described on Community Catalyst's website to achieve these past victories. So, it was second nature for us to use them in developing our End Medical Debt Campaign. These capacities are: (1) policy analysis; (2) developing and implementing a campaign; (3) building an active grassroots network; (4) communications strategy; (5) building strong coalitions and alliances; and (6) generating resources.

1. Policy Analysis: What exactly is the problem…?

Policy analysis is a fancy way of describing a problem and identifying the reforms that will help fix it. New York advocates used several bellwether strategies, described here, to better understand the nature and extent of the medical debt problem for patients.

Polling: In January 2019, Altarum conducted a statewide poll that found that over half (52%) of New Yorkers experienced an affordability burden in the prior year.[5] Thirty-five percent experienced one or more of these struggles in order to pay their medical bill: used up their savings (15%); were unable to pay for basic needs like food, rent, heat (13%); contacted by a collection agency (12%); borrowed money to pay a bill (9%); racked up credit card debt (7%); or were placed on a long-term payment plan (6%). To make matters worse, over 75 percent of the people surveyed were worried about being able to afford healthcare in the future.

JOHN W. INGRAM



"I never expected the last two three years of my life would be like this, but it has turned into an absolute, complete nightmare," says John W. Ingram, describing the multiple medical bills he received from doctors and hospitals. John came to New York's consumer assistance program with a bag full of incomprehensible medical bills. Despite his Medicare coverage, he had been put into collections and sued, and he was pessimistic that anyone could make sense of the financial chaos that resulted from his chronic illnesses. Sadly, he was right: John died on August 22 , 2019, still fighting off his medical creditors. John explains his struggle with overwhelming medical debt in his own words in this *We the Patients* video.

Consumer experiences reported to direct service providers: Simultaneously, lawyers and advocates working for New York's independent consumer assistance program, Community Health Advocates, started reporting a surge in

5 Altarum Healthcare Value Hub, "New Yorkers Struggle to Afford High Healthcare Costs; Support a Range of Government Solutions Across Party Lines," March 2019, available at: https://www.healthcarevaluehub.org/advocate-resources/publications/new-yorkers-struggle-afford-high-healthcare-costs-support-range-government-solutions-across-party-lines

medical debt cases to the policy team at the Community Service Society of New York (CSS), which administers the CHA network as well as the Health Care for All New York coalition. Looking at the data, the CSS team realized that CHA had witnessed a 64 percent increase in medical debt cases between 2019 and 2020. CHA advocates described how hospitals were suing patients and that patients were being bombarded by duplicative and multiple bills for single episodes of care.

Analysis of on-line public court filings: Looking online at public court records, the CSS team realized that some hospitals were suing thousands of patients. In the summer of 2019, CSS deployed an army of interns to go the courthouses and photocopy a random sample of case files for each hospital. An analysis of those files revealed that hospitals were able to sue patients as long as six years after the episode of care. Patients felt this was very unfair because they no longer remembered why they were in the hospital, why their insurance company may not have paid the bill, and often no longer had the same insurance company, so they had no ability to remedy the matter. Further analysis of the zip codes in which patients lived suggested that many of the people who were sued should have qualified for hospital financial assistance. We also discovered that many hospitals—all of whom are non-profit 501(c)(3) charities under state law—were charging patients the maximum (commercial) judgment interest rate of 9 percent, were taking liens on patients' homes, and garnishing their wages.

…and how do we fix it?

Approaching hospitals directly: Taking a page from union organizing, the CSS team then embarked upon a long "pattern bargaining" campaign in which we analyzed a random sample of court files for one hospital after another. We then wrote letters to their leadership detailing their court practices, describing how many of their cases were filed in low-income communities of color (using zip codes and census data), and asking them to offer financial assistance in lieu of suing their patients. (See Appendix on page 15 for an example). This process was very labor intensive, but had some early successes, including one hospital system ceasing the practice of suing patients altogether and another hospital agreeing to revisit their financial assistance policies and terminate their practice of charging 9 percent interest.

Policy reports: CSS also issued a series of Discharged Into Debt policy reports describing the findings from our analysis of the public court cases. Looking at the public court on-line website, our researchers identified over 50,000 medical debt cases, located several medical debt regional "hot spots," and identified a list of the "dirty dozen" most aggressive New York hospitals that sue patients. The report also found that the median amount of these cases was just $1,900, which is a substantial amount of money for patients, but does almost nothing to improve the hospital's bottom lines, even when considering the aggregate amount. Finally, these reports emphasized that many of the hospitals that sue patients most aggressively simultaneously receive vast payments in Disproportionate Share Hospital funding, called the Indigent Care Pool in New York.

Presentations, story gathering and focus groups conducted by advocacy partners: Meanwhile, HCFANY had received funding from the New York State Health Foundation to work on consumer empowerment and support the HCFANY Transparency Project. Several HCFANY partners, including Raising Women's Voices/CC Women's Health Project, conducted grassroots research by making presentations, gathering stories and conducting focus groups. From those focus groups, we found additional medical debt pain points, including: facility fee

charges for preventive care like mammograms, providers requiring patients to sign "assumption of financial liability" forms.

Drafting a law: Pulling together all these issues and working closely with our Assembly and Senate Health Chairs, Assemblymember Richard Gottfried and Senator Gustavo Rivera, HCFANY identified the following legislative fixes that could help address these problems. Eventually, these fixes were compiled in a package of bills dubbed the Patient Medical Debt Protection Act:

- Cut the statute of limitations for providers to sue patients from six to three years;
- Reduce the 9 percent judgment interest rate for medical debt to the U.S. Treasury rate;
- Modernize our state's Hospital Financial Assistance law to require one uniform application and expand income eligibility limits;
- Ban facility fees for preventive care;
- Adopt a uniform patient "assumption of financial liability" form;
- Require hospitals to issue one consolidated bill of all the bills related to one hospital stay;
- Close the remaining loopholes in the State's Surprise Bill law; and
- Bar hospitals from taking liens on patients' homes and garnishing patients wages.

Working with our state legislative champions, this agenda has evolved over time. For example, one important goal that has proven challenging is the "one visit, one bill" provision, which seeks to shield patients from receiving duplicative, confusing bills from many providers related to one hospital stay or service. This concept tried to protect patients like John Ingram (see details on page 4) and another patient, Chandak Ghosh, who told the Campaign about receiving 27 different bills after being hospitalized with kidney stones.[6] Another part of the agenda was to fix a loophole in the Surprise Bill law by holding patients harmless when they have received erroneous information from their plan or provider about being in-network. This fix is for patients like Claudia Knafo, (see details on page 7) who was billed $101,000.

A DIAGNOSIS OF KIDNEY STONES LEAVES PATIENT WITH 27 DIFFERENT BILLS

- Chandak Ghosh's Story

After experiencing severe back and stomach pains in 2010, Chandak was rushed to the emergency room at Mt. Sinai West. He spoke with a number of specialists to reach the correct diagnosis. Ultimately, a CT Scan determined Chandak was suffering from kidney stones.

Even though he was fully insured, Chandak started receiving a litany of bills over the next few days – 27 in total, from the hospital emergency department, emergency physician, gastroenterologist, nephrologist, radiologist, laboratory and radiology department. Each bill threatened to damage his credit if they weren't paid promptly. According to Chandak, handling 27 separate bills with aggressive language was "extraordinarily draining emotionally and psychologically."

Story adapted from We The Patients.

6 Guest Post: A Diagnosis of Kidney Stones Leaves Patient with 27 Different bills – Chandak Ghosh, NYC, We the Patients, available at: https://wethepatientsny.org/guest-post-a-diagnosis-of-kidney-stones-leaves-patient-with-27-different-bills-chandak-ghosh-nyc/.

$101,000 SPINAL SURGERY
- Claudia Knafo's Story

When Claudia Knafo needed spine surgery in 2012, she did her homework. She interviewed multiple surgeons, found one whose website claimed accepted her insurance and called the doctor's office to confirm he was in network.

While recovering from the successful surgery, Claudia got bad news: The surgeon wasn't in network, and the website that listed her insurance company was incorrect. Her surgeon charged $101,000 for the operation, of which her health plan only covered $66,000. Making matters worse, the insurer reached out a second time to say they'd made a mistake and had overpaid the doctor. They told Claudia she needed to get the $66,000 back from her surgeon — who had no intention of parting with the money. She called the experience "a nuclear attack."

Now, Claudia is a fierce advocate for health reform, working with We The Patients to call for an end to unfair medical billing practices for all New Yorkers.

Original story appeared in Vox, with follow-up on We The Patients.

for an out-of-network surgery performed by a doctor selected from her provider directory.[7] This provision has also been dropped because it appears to be addressed by the federal No Surprises Act.

2. Developing and Implementing a Campaign

In October 2019, the HCFANY steering committee met to discuss our legislative organizing agenda and campaign plan. To design an effective medical debt campaign strategy meeting, HCFANY typically begins with a basic power analysis. Based on the Midwest Academy's training, a power analysis is an exercise that helps campaign organizers identify targets, constituents, allies and opponents, and tactics.

Adopting a bill package to organize around. Ending medical debt is substantively a boring topic. It just is. There are many constituent parts to a problem that is as complex as the rest of the American healthcare system. To make New York's End Medical Debt Campaign (the Campaign) comprehensible, and thus viable, we decided to take all the component legislative pieces of our bill and ask our legislative champions to introduce a "package" of component bills called the Patient Medical Debt Protection Act (PMDPA). While the Campaign goal was to enact as many provisions of the PMDPA as possible, HCFANY leaders understood that, in the end, only one or two pieces would be enacted at a time—and some pieces may never be enacted at all.

Enacting legislation in New York can be a cumbersome process. A bill is introduced and voted upon by the committee of jurisdiction in both houses. After that, the bill can be slowed down by being sent to another committee (e.g. Rules or Ways and Means) to consider any financial or legal implications. When all these committees approve a bill, it will be placed on a calendar for a full floor vote in both chambers, where it may languish or be voted upon. Once a bill passes both houses, it must be called up by the Governor, who will consider it for signature.

7 Anemona Hartocollis, "New York Curbs Medical Bills Containing Surprises," *New York Times*, March 30, 2014, see also, https://wethepatientsny.org/claudia-knafo-of-famed-101000-spinal-surgery-continues-to-fight-surprise-medical-bills/

The Governor has until December 31 to call a bill up for signature. Each stage of this process requires intensive advocacy. For this reason, enacting laws in New York is easily a two- to four-year odyssey—notwithstanding its reputation as a progressive state.

There are significant Democratic majorities in both houses and the Governor (first Governor Cuomo, and since August 2021, Governor Hochul) is also a Democrat. But a Democratic trifecta does not easily translate into a patients-first agenda. Taking on the hospitals in a state like New York is often considered a fool's errand. The hospitals are the largest employer in New York—and almost every legislator has at least one hospital in their district. Together, the hospitals and their closest union partner (SEIU/1199), spend more lobbying dollars than any other sector in Albany.[8]

Identifying opponents: While the public hospital system in New York City was supportive of idea of improving medical debt practices, their private and voluntary counterparts often are not. Our strategy to deal with the hospitals was to continue to meet with them individually and issue public reports on the collective practices of hospitals across the state.

Identifying allies: HCFANY then identified and engaged with many allies including health care unions that were supportive (e.g., the nurses' union), senior groups (e.g., AARP and Statewide Senior Action), children's groups, anti-poverty organizations and legal services, and groups representing people of color (e.g. NAACP, the Urban League, Hispanic Federation). Many of these groups were already active in the HCFANY Steering Committee.

Tactics: We then outlined the legislative timeline of our session, which runs from January through June, with key opportunities to influence legislation through the following vehicles: the Governor's State of the State (early January); the Governor's budget (late January); the two "One House" budget bills (each house issues its own budget blueprint in February or early March); the compromise budget (by April 1); and the remaining two months of session (ends in early June). Many of the Campaign's agenda items have the advantage of no fiscal impact. However, the New York State budget often enacts policy changes, which makes January through April just as important for the Campaign's non-budgetary goals as May and June. We then identified tactics that could potentially inform and influence each of these steps, including:

- lobby visits with the Executive branch;
- in-district lobby visits with tailored materials detailing the number of lawsuits brought against patients in that district;
- memoranda of support by individual groups;
- collective letters of support seeking passage;
- social media and earned media (described in greater detail below); and
- testifying about the issue at various legislative hearings (e.g., budget hearings, COVID pandemic response hearings).

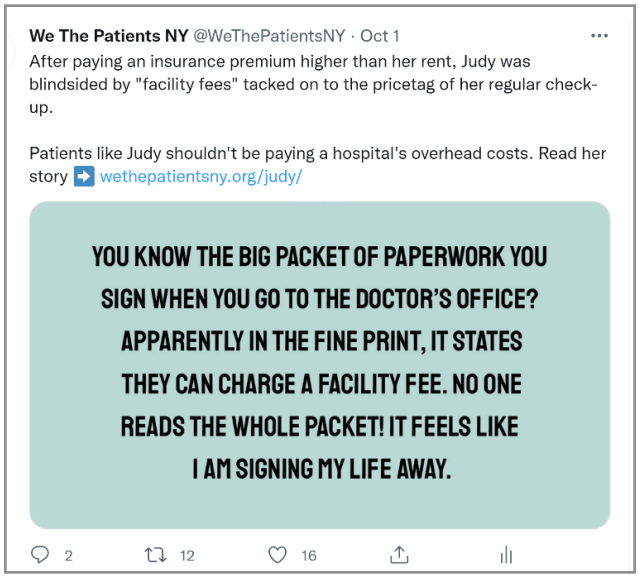
3. Building an active grassroots network

HCFANY's campaigns usually have some financial resources to support grassroots organizing. However, there has been substantial "donor fatigue" in supporting health care coverage and affordability campaigns—largely due to the real and perceived success of the ACA in reducing the rates of the uninsured. But the consumers HCFANY represents feel that health care continues to cover less and cost more. These allegedly anecdotal views are validated by numerous

8 J. David Goodman, "A Lobbyist Gave $900,000 in Donations. Whose Money Is It?," *The New York Times*, August 26, 2019.

quantitative studies, including the 2019 Altarum poll in New York.

The New York State Health Foundation, however, was interested in supporting a novel approach to grassroots organizing that consists of going to where the patients often are: online. CSS adopted a digital organizing strategy to identify, engage, and train patients to advocate for a more patient-centered health care system with a project called We the Patients (WTP). Since April 2019, WTP posts have been placed in one million digital feeds and seen by over 500,000 users. Consumers have engaged with WTP content over 22,000 times. The WTP platforms have well over 5,000 followers in both Instagram and Twitter and a vibrant Facebook group of over 7,000 patients. Using interns, the WTP program has created viral TikTok videos profiling the patient experience with the health care system. Linking with CSS's Phone-To-Action platform, patients can engage directly with their elected official on matters that are important to them, including the #EndMedicalDebt Campaign. This effort paid off by earning several new legislative co-sponsors for the Patient Medical Debt Protection Act who had been contacted directly by constituents but did not yet have relationships with the Campaign.[9]



Two of HCFANY's Transparency Project organizations are grassroots organizations with large memberships, Make the Road NY and Citizen Action NY. These two groups educated their staff and membership about the End Medical Debt Campaign through regular trainings and

9 S6757/A8639 (2019-2020 N.Y. Legislative Session).

meetings. Other Transparency Project members spoke about the Campaign in meetings and presentations for other grassroots organizations. During the pandemic, in-person meetings have been replaced by zoom meetings and trainings. HCFANY also holds statewide meetings twice a year that convene grassroots organizations and advocacy groups to discuss HCFANY's agenda, and we focused on the End Medical Debt Campaign in each of these meetings.

4. Building strong coalitions and alliances

The End Medical Debt Campaign has been an opportunity to elevate the profound racial disparities in health care in New York. For example, in Rochester, people of color are 271% more likely to have medical debt than white people. This disparity is reflected throughout the state: in Westchester County it is 267%; in Syracuse it is 193%; and in Brooklyn, it is 133%. Working closely with the Urban League and the Hispanic Federation, HCFANY was able to secure a workshop hosted by Health Committee Chair Gustavo Rivera at the 2021 Black, Puerto Rican, Hispanic and Asian Legislative Caucus weekend.

HCFANY has also partnered with many other allies who are supportive, but not necessarily members of our coalition, including the New York Public Interest Research Group, the American Association of Retired Persons/NY Chapter (AARP), the NAACP of NY, Doctors Council, and the New York State Nurses Association. These partners were pivotal for the Campaign's success. For example, AARP of NY was willing to use its robust activist email list to generate patient engagement with the legislature in support of the Patient Medical Debt Protection Act. We have also forged closer alliances with other coalition partners such as The Commission on the Public's Health System and Medicaid Matters New York. All these partners were willing to provide memoranda of support for the bill—generating a large number of these memoranda is an important tactic for the successful enactment of legislation in Albany.

The Consumer Coalition Cavalry. Another group of allies are a broad coalition of consumer debt advocates, called New Yorkers for Responsible Lending.[10] They also sought to reduce the civil court interest judgment rate and had a parallel bill that had been drafted by a group of law students at Fordham University. Working with these advocates, HCFANY soon discovered that their bill was broader than the interest rate provision in our legislative package because it would cover medical debt as well as other types of consumer debt cases (e.g., education, credit card debt). Moreover, their standalone bill would be retroactive, so it would cover older judgments from the past, not just the future medical debt judgments covered by our bill.

In early 2021, HCFANY was supportive of all three proposals to reform the civil judgment interest rate: the Governor's proposal to adopt the U.S. Treasury rate for all cases, which was included in his Executive Budget bill;[11] HCFANY's proposal that only applied to medical debt;[12] and the New Yorkers for Responsible Lending-supported bill which covered all con-

10 New Yorkers for Responsible Lending is a statewide coalition of over 170 organizations working for fair and affordable financial services. It was started in 2000 and includes community financial institutions, labor unions, legal services groups, community groups and non-profits.

11 The Governor's Executive Budget Proposal sought to adopt the U.S. Treasury rate of interest in all civil court judgment cases. https://www.budget.ny.gov/pubs/archive/fy22/ex/artvii/ppgg-bill.pdf (page 129).

12 S3057/A1538.

sumer debt.[13] After many strategic discussions, HCFANY joined forces with the consumer debt groups to support their bill—which ultimately was adopted by both houses in June 2021.

The Insurers' assist. Another important issue for the End Medical Debt Campaign was an effort to close a loophole in New York's Surprise Bill law that exempted out-of-network (OON) hospital emergency room visits from the Independent Dispute Review (IDR) process. Patients often received these bills for OON hospital ER charges, but the 2015 Surprise Bill law forced the health plans to pay them, even if they were excessive. So, while patients were nominally protected, the excessive charges negatively impacted the premiums that consumers and employers pay. To close that loophole, HCFANY members—led by Consumers Union—worked closely with the Health Plan Association, the State insurance industry trade group, to secure enactment of a law that would treat OON ER charges the same way that other surprise OON bills are treated. If there is either an underpayment, or an overpayment, the insurers or providers can potentially request review through IDR. The bill further required health plans to pay a reasonable amount to hospitals when they receive the OON ER bill. The hospital associations vehemently opposed this bill, but ultimately it was enacted as part of the 2020 state budget, with a small carve out for safety net hospitals. Legislative leadership was persuaded to support the bill by a broad range of consumer, labor and business groups who joined the ad hoc coalition.

The academics' surprise. Based on our research, we found that the single most aggressive medical debt collector in the state is the non-profit Northwell hospital system—New York's largest hospital network. This system's leader was a close ally of former Governor Cuomo and was routinely tasked by the governor to address important problems, such as the health crisis in central Brooklyn or the administration of the first COVID-19 vaccine in the state. When approached with data indicating that it disproportionately sued patients in New York, Northwell was unrepentant. Not even a front-page story in The New York Times profiling the thousands of cases it had brought during the pandemic persuaded them to stop suing patients. But in June 2021, all that changed. Johns Hopkins and Axios released a report of national hospitals' debt practices that listed two of Northwell's hospitals in the top ten list in their analysis of total court actions brought by the top 100 hospitals in America.[14] The academics' report appears to have been the proverbial straw that broke the camel's back: the next day, Northwell announced the appointment of a "medical debt ombudsman."

5. Communications strategy

Engaging with earned media can be a difficult achievement for many advocacy campaigns: reporters studiously avoid "advocates advocate for a bill" press conferences. However, when people from communities across the state share their personal experiences, these medical debt stories provide a better hook for reporters than focusing just on the policy issues. They are inherently dramatic and they describe situations which most people who have accessed health care in the United States have either experienced or fear. Further, the COVID pandemic helped focus the media's attention on the End Medical Debt Campaign for two reasons. First, health care was squarely in the news and reporters were routinely looking for new ways

13 S5724B/6474B

14 Caitlin Owens, "America's Biggest Hospitals vs. their patients," Axios, June 14, 2021, available at: https://www.axios.com/hospitals-patients-lawsuits-billing-4bfa93b2-3bbf-48a5-b8e2-2f8a68c533a9.html

The New York Times

One Hospital System Sued 2,500 Patients After Pandemic Hit

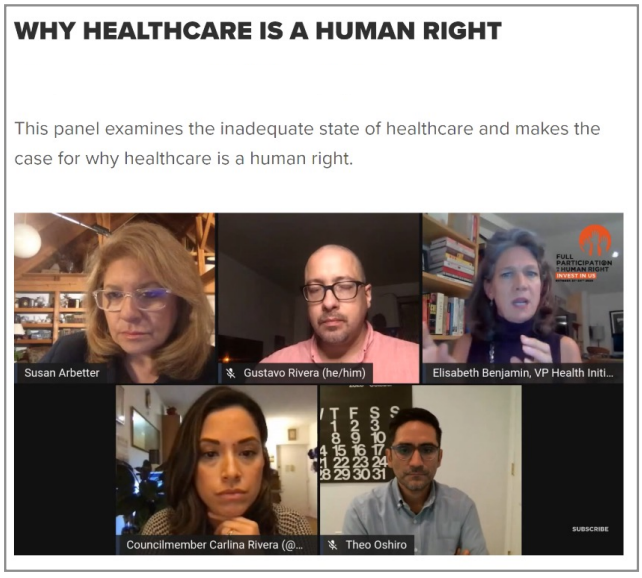
The largest health system in New York, led by a close ally of the governor, continued to sue over medical debt during the Covid-19 crisis, even after other big hospitals suspended lawsuits.

509

to report about the pandemic. The specter of COVID patients being saddled with enormous hospitals bills provided helpful fodder for our campaign. Second, the pandemic forced many reporters and legislators to work remotely opening up more opportunities for well-attended web events.

The Discharged Into Debt series of reports provided excellent opportunities for media engagement. For example, Discharged Into Debt: A Pandemic Update was a report that documented how the same set of hospitals that were aggressively suing patients before the pandemic were maintaining the practice during the pandemic, when the courts were effectively closed to the public and patients had no ability to go to court to defend themselves. Working with Pulitzer-prize winning reporter Brian Rosenthal of The New York Times, the CSS team was able to secure court files for him to review. As a result, his story, our report, and the End Medical Debt Campaign landed on the front page of the January 5, 2021, edition of The New York Times. Continuing this strategy, CSS issued a third report in the series, Discharged Into Debt: Racial Disparities and Medical Debt in Albany County, which was profiled on the front page of the Albany Times Union on March 18, 2021.

Political reporters proved to be especially interested in this issue. New York has a state capitol podcast, called the Capitol Pressroom, that is routinely listened to by key stakeholders and policymakers. Campaign members were interviewed several times for that show.[15] Another strategy was to invite the Capitol Tonight host, Susan Arbetter, to join a web-streamed Why Healthcare is a Human Right panel hosted by City and State New York media outlet, with a Campaign member, and Senator Rivera to discuss the upcoming health agenda in the coming legislative session.



HCFANY also tried out a new social media strategy that has helped us work more closely with other New York advocates. Many of HCFANY's lead organizations have staff dedicated to social media, but these communications staff members do not join HCFANY's bi-monthly Steering Committee calls. Information about policy and messaging didn't always trickle back to them from the policy-oriented staff on the calls.

15 Capitol Pressroom: Financial downturn exacerbates medical debt burden, November 13, 2020, https://capitolpressroom.org/2020/11/13/financial-downturn-exacerbates-medical-debt-burden/
Capitol Pressroom: Protections from growing medical debt missing from budget priorities, March 19, 2021, https://capitolpressroom.org/2021/03/19/protections-from-growing-medical-debt-missing-from-budget-priorities/

We theorized that connecting these social media staff to each other and directly providing them with health care content might increase engagement with HCFANY and We the Patients' social

media accounts. To test this idea, we invited the social media teams from HCFANY's lead organizations, along with social media staff at other health advocacy organizations around the state, including Navigator organizations and groups WTP interacted with on social media, to join a new Social Media Workgroup.

WTP's Digital Organizer convened a series of introductory calls to learn from the participants how best to work together to amplify their messages. During the first call, with 40 attendees, it became clear that participants split into two groups: advocates already very active on social media looking for ways to connect, and advocates (including direct service providers like Navigators) seeking training. We surveyed call participants to solicit more information about their experience and interests and created a two-track plan to serve both constituencies. We created a Slack channel that now has 118 participants, where seasoned social media users can share information about their campaigns. For those new to social media, we incorporated trainings and materials (e.g., learning community conversations and social media tool kits) in the group calls and emails. For example, WTP's student interns led a training on how to produce TikTok videos on a monthly call.

6. Generating resources

The End Medical Debt Campaign cobbled together resources from a variety of disparate sources to support our work.

Kicking us off was the generous offer from Altarum's Health Care Value Hub to partner with HCFANY to conduct a statewide poll that help build a quantitative case that medical debt was a significant problem for New Yorkers. We were also fortunate that the New York State Health Foundation was eager to test the model of organizing patients' experiences through social media platforms and funded the We The Patients project. HCFANY coalition members were also eager to leverage our consumer empowerment/transparency grant to elevate the medical debt agenda, among other Campaign goals. Finally, thanks to all this organizing and the issuance of the first Discharged into Debt report, CSS was approached by Robin Hood, a New York City-based major funder that wanted to participate in resourcing the End Medical Debt Campaign. With this final grant, the Campaign was able to fund a lawyer and three legal interns who could pull a representative sample of court files to analyze the conduct of the most aggressive hospitals in the State. These files formed the basis of CSS-written letters to hospitals and additional Discharged Into Debt reports.[16]

16 *Discharged Into Debt: A Pandemic Update* (January 2021), *Discharged Into Debt: Racial Disparities and Medical Debt in Albany County* (March 2021); and *Discharged Into Debt: Nonprofit Hospitals Take Liens on Patients' Homes* (2021).

PROGRESS TO DATE AND NEXT STEPS

To date, New York's End Medical Debt Campaign has had some major victories. First, we were able to engage directly with several hospitals and convinced them to either stop suing patients entirely or to substantially reform their conduct. New York's largest hospital system, Northwell, for example, has established a Medical Debt Ombudsman. Second, in 2020 we were able to enact two provisions of our Campaign – curbing the statute of limitations in medical debt cases from six to three years and closing the emergency room loophole in our State's Surprise Bill law. Third, in 2021 in coalition with the New Yorkers for Responsible Lending, we were able to enact the broad-reaching Fair Consumer Judgment Interest Rate bill that will cut the interest rate in consumer debt—including medical debt— from 9 to 2 percent.

But we have much more work to do. Hospitals can still file liens on patients' homes and garnish their wages. Our State's Hospital Financial Assistance law remains unwieldy and out of date. Patients still face complex and indecipherable bills for charges like facility fees.
The next phase of the Campaign will focus more on grassroots organizing and building a tighter coalition.

LESSONS LEARNED

Consumers get it. When we first started working on these issues, we wondered if the technical fixes were too complicated for consumers to understand. The reality is that consumers are experiencing these issues and they're mad about it! When we spoke about specific problems, like facility fees, consumers understood exactly what we were talking about: "Those facility fees are just like resort fees!" Consumers are willing to tell their stories and advocate for solutions.

Legislators were quick to take action. We were surprised by how quickly legislators acted to sponsor medical debt protection bills. Legislators like to move no-cost bills when state budgets are tight. Unlike our typical expensive "asks" to expand coverage to new groups of people, medical debt reform does not cost the state money!

It's important to demonstrate the racial equity impacts of medical debt. For many of our campaigns, we know that there is a racial equity impact of the issue, but we don't have data to back it up. There are some great sources of data on the racial equity impact of medical debt, however. The COVID-19 pandemic also highlighted racial disparities in access to affordable care and medical billing issues and increased media interest in covering these issues.

Medical debt campaigns can attract new partners. HCFANY is always working to build new partnerships, and we were able to work with several new partners through the End Medical Debt Campaign. For example, HCFANY joined forces with other consumer debt advocacy groups to work on a measure that would reduce the interest rate for all consumer debt. And organizations of color, including the NAACP and the Urban League, wrote or signed on to memos of support for the medical debt protection legislation.

Appendix

Click here to see an example of a Community Service Society of New York Letter to a Non-Profit Hospital's Executives