

ADMINISTRATIVE COMPLAINT

Centralized Case Management Operations
U.S. Department of Health and Human Services
Office for Civil Rights
200 Independence Avenue, SW
Room 509F HHH Building
Washington, DC 20201

Steven Mitchell, Acting Regional Manager
U.S. Department of Health and Human Services
Office for Civil Rights
233 N. Michigan Ave., Suite 240
Chicago, Illinois 60601

RE: DISCRIMINATORY QUALIFIED HEALTH PLAN OFFERINGS IN IOWA

COMPLAINANTS

National Hemophilia Foundation
7 Penn Plaza
New York, New York 10001

Hemophilia Federation of America
820 First St, NE
Washington, District of Columbia 20002

Hemophilia of Iowa
6300 Rockwell Drive NE
Suite 104
Cedar Rapids, Iowa 52402

The National Hemophilia Foundation (“NHF”) is a not-for-profit organization dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. Established in 1948 NHF has chapters throughout the country. Its programs and initiatives are made possible through the generosity of individuals, corporations and foundations as well as through a cooperative agreement with the Centers for Disease Control and Prevention (“CDC”). The NHF maintains a presence in Iowa through its affiliate, Hemophilia of Iowa.

Hemophilia Federation of America (“HFA”) formed in 1994 as a place of education and support for bleeding disorders families. HFA is a national nonprofit that assists and advocates for the bleeding disorders community and is comprised of 44 Member Organizations across the country, including Hemophilia of Iowa. Its vision is to remove barriers to choice of treatment and to

improve the care and quality of life for all people with bleeding disorders. HFA is funded through the support of a cooperative agreement with the CDC, as well as through individual and corporate donations.

Hemophilia of Iowa provides education and support for people with bleeding disorders and their family and friends. Hemophilia of Iowa provides information, advocacy and support for the bleeding disorders community through its partnership with the staff of the University of Iowa Hemophilia Treatment Center, industry, government, and other resources. Their goal is to assist anyone in Iowa affected with a blood coagulation disorder to become healthier and more self-sufficient.

DEFENDANT

Wellmark Inc., is an insurer which offered Qualified Health Plans (“QHPs”) in Iowa through 2017 under the name “Wellmark Blue Cross and Blue Shield”.

JURISDICTION

This complaint is filed pursuant to Section 1557 of the Patient Protection and Affordable Care Act (“ACA”), codified at 42 U.S.C. § 18116. Section 1557 prohibits any health program or activity that receives federal financing (including contracts of insurance sold through the health insurance Marketplaces) from discriminating against individuals living with disabilities, including hemophilia. The Department of Health and Human Services’ (“HHS”) Office of Civil Rights (“OCR”) has primary responsibility for ensuring compliance with Section 1557 through investigations and enforcement action. The Department of Justice (“DOJ”) has coordinating responsibility pursuant to Executive Order 12250.¹

PRELIMINARY STATEMENT

Under the ACA, health insurers may not discriminate on the basis of disability. Section 1557 and other ACA provisions prohibit discriminatory health insurance practices, including plan benefit designs which discourage enrollment of persons with significant health needs, including people living with hemophilia.

Wellmark has a long history of discriminating against and intimidating those with hemophilia. Wellmark has gone to extreme lengths to avoid covering hemophilia claims—including restrictive policies and tactics to deny covering hemophilia medications, particularly prior to the enactment of the ACA. Beginning in 2008, Wellmark began to investigate a pharmacy in Iowa which was dispensing a large volume of expensive hemophilia medications.² Emails between Wellmark’s pharmacy director and Wellmark investigators show extensive collusion to deny valid hemophilia claims for any reason, legitimate or not.³ Wellmark has used intimidation to drive away

¹ Exec. Order No. 12,250, 3 C.F.R. 298 (1980).

² See *T. Zenon Pharmaceuticals, LLC v. Wellmark, Inc.*, 2015 WL 9450469 (Ct. App. Iowa Dec. 23, 2015).

³ See *id.* (providing emails from Wellmark and Blue Cross Blue Shield discussing their “strategy” of denying hemophilia pharmacy claims based on a claimed lack of “documentation”. In another email, employees of Wellmark – unable to find fault with the documentation for the pharmacy’s submitted claim -- discussed “another [reason] for

hemophilia patients. In April 2009, Wellmark went as far as demanding an in-home visit to a hemophilia patient's home to review the patient's infusion logs (despite the fact that the patient agreed to mail the records to Wellmark instead). During the home visit, Wellmark also falsely told the patient's parents that the cost of hemophilia medication the patient was receiving had gotten "really close" to their lifetime cap of \$1 million.⁴ Rebuking Wellmark's denial tactics, on December 23, 2015, the Iowa Court of Appeals ordered Wellmark to pay a pharmacist for hemophilia medication that had been validly been dispensed to 24 hemophilia patients, mostly children. The court ordered Wellmark to pay for 114 valid claims totaling approximately \$7 million plus interest.⁵

Having failed to prevail in court, and with new safeguards put in place by the ACA, Wellmark moved on to new strategies to discriminate against hemophilia patients. On April 3, 2017, Wellmark announced it would not sell or renew individual and family ACA plans in Iowa effective January 1, 2018.⁶ Wellmark stated that it was choosing to withdraw from the Iowa Marketplace because it had lost approximately \$90 million in the Marketplace since 2014 and because of continuing uncertainty over the future of the Marketplaces.⁷

While Wellmark has publicly provided the above reasons as its basis for withdrawing from the Marketplace, it has also publicly stated that its withdrawal is attributable to the requirement that it provide coverage to patients with hemophilia. For example, on March 30, 2017, Laura Jackson, Executive Vice President for Health Care Innovation & Business Development at Wellmark spoke at a meeting of the Rotary Club of Des Moines, Iowa. There she publicly disclosed, without the consent of the patient, that Wellmark was providing health insurance coverage to a "17-year-old hemophiliac" patient at a cost of \$1 million a month ("the Patient").⁸ Ms. Jackson's remarks were reported in the press.⁹ Wellmark's statements demonstrate a clear intent to deny a patient coverage based on their health condition—a violation of the ACA.

Prior to Wellmark's disclosure, on September 28, 2016, Wellmark announced it would discontinue offering Marketplace plans for the 2017 plan year in all but 40 Iowa counties.¹⁰ (Iowa has 99 counties.) Among the counties Wellmark discontinued offering Marketplace plans in was

rejection [of the pharmacy claim]" to "hold [the insured's pharmacy] as long as I can.").

⁴ See *id.* (the patient's father testified at trial that Wellmark's statement regarding the patient nearing the lifetime cap was false because the patient had only used approximately 10% of the limit).

⁵ *T. Zenon Pharmaceuticals, LLC v. Wellmark, Inc.*, 2015 WL 9450469 (Ct. App. Iowa Dec. 23, 2015).

⁶ Press Release, Wellmark, Wellmark announces 2018 individual ACA market decision in Iowa (Apr. 3, 2017), <https://www.wellmark.com/about/newsroom/2017/04/03/2018-aca-market-decision>; see also Iowa Insurance Division, 2017 County Listing for On Exchange Coverage, <https://iid.iowa.gov/documents/press-releases/2017-county-listing-for-on-exchange-coverage> (providing a list of all Iowa counties and the insurers offering Marketplace plans in those counties).

⁷ *Id.*

⁸ Laura Jackson, Executive Vice President Executive Vice President for Health Care Innovation & Business Development at Wellmark, Address at the Rotary Club of Des Moines IA (March 30, 2017), <https://portal.clubrunner.ca/1637/Stories/laura-jackson-wellmark>. The calendar date for the speech is available at: <https://portal.clubrunner.ca/1637/Events/Calendar> (click "March 2017").

⁹ See Section III *infra*.

¹⁰ Wellmark, Wellmark announces individual ACA market changes in Iowa and South Dakota (Sept. 28, 2016), <https://www.wellmark.com/about/newsroom/2016/09/28/wellmark-announces-individual-aca-market-changes-in-iowa-and-south-dakota>.

the Patient's county.¹¹

In addition, Wellmark's disclosure of the Patient's information raises significant concerns regarding protections afforded to him by the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), as codified at Social Security Act § 1171 *et seq.* Information on a patient's age, gender, and diagnosis would not automatically be considered identifying information under HIPAA, but HIPAA is triggered if "there is a reasonable basis to believe that the information can be used to identify the individual."¹² According to the family of the 17-year old with hemophilia, Wellmark's public disclosure of their son's information has led to the identification of the Patient by the public and media. This is not surprising given that Wellmark revealed the Patient's age, disease, and state of residence.

Hemophilia affects primarily males with a frequency in the United States of only 1 in 5,000 births. There are only about 126,834 males between the ages and 15 and 17 in Iowa.¹³ Thus, there are only about 25 male hemophiliacs in Iowa between the ages of 15 and 17. Given the rarity of the condition and Wellmark's relatively full description of the individual, most neighbors would be able to identify the Patient in short order. The Wellmark representative revealed so much personally identifiable information and his ailment just as assuredly had she spoken his name or flashed his likeness on the screen, in violation of HIPAA. Wellmark should be held accountable for this breach of privacy and of federal law.

DISCUSSION

I. ACA Anti-Discrimination Protections

Prior to the ACA, health insurance companies routinely discriminated against people living with pre-existing conditions, including hemophilia. Plans denied coverage to individuals with pre-existing conditions and could exclude coverage of treatments for those conditions. Additionally, insurance companies imposed annual and lifetime caps on benefits, which disproportionately affected people living with chronic lifetime diseases, such as hemophilia.

The ACA was enacted to end discriminatory health insurance practices which disproportionately affected individuals with chronic lifetime diseases. Thus, the ACA requires guaranteed issue of coverage in the individual and small group health insurance markets. Individuals cannot be denied health insurance or coverage due to a preexisting condition.¹⁴ The ACA further prohibits discrimination against individual participants and beneficiaries based on health status or medical condition,¹⁵ and it prevents insurers from imposing annual or lifetime limits on benefits.¹⁶ Prior to the ACA, annual or lifetime caps effectively meant hemophilia patients could not receive coverage for their condition. This is so even with caps

¹¹ Two other insurers continued to offer Marketplace plans in the Patient's county for 2017.

¹² 45 CFR 164.514.

¹³ UNITED STATES CENSUS, *2015 American Community Survey: Iowa*, https://factfinder.census.gov/bkmk/table/1.0/en/ACS/15_5YR/S0101/0400000US19.

¹⁴ 42 U.S.C. § 300gg-1.

¹⁵ 42 U.S.C. § 300gg-4.

¹⁶ 42 U.S.C. § 300gg-11.

set as high as \$1 million: some hemophilia patients would reach this cap before entering kindergarten. The significant cost of insuring hemophilia patients is not news to health insurers—in electing whether to offer insurance in a Marketplace a sophisticated insurer must account for the potential costs it will incur to provide coverage to all patients, regardless of their health condition.¹⁷

The ACA contains additional provisions barring discriminatory plan benefit design. The Act states that a QHP may “not employ marketing practices or benefit designs that have the effect of discouraging the enrollment in such plan by individuals with significant health needs.”¹⁸ ACA regulations prohibit discrimination on the basis of race, color, national origin, disability, age, sex, gender identity, or sexual orientation.¹⁹

A. Section 1557 Protections

The ACA applies several existing federal anti-discrimination and civil rights statutes, including the Rehabilitation Act, to the QHPs offered through the health insurance Marketplaces. Prior to the ACA, private health insurance plans were not subject to the Rehabilitation Act, which prohibits discrimination in federal programs against persons living with disabilities, including hemophilia. Under Section 1557 of the ACA, the Rehabilitation Act expressly applies to the “contracts of insurance” available in the Marketplaces:

An individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), the Age Discrimination Act of 1975 (42 U.S.C. 6101 et seq.), or section 794 of title 29 [the Rehabilitation Act], be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title (or amendments).²⁰

Section 1557 expressly identifies “credits, subsidies, [and] contracts of insurance” as federal financial assistance to make clear that each trigger its application. Unlike Section 1557, Title VI, Title IX, and the Rehabilitation Act either explicitly exclude or have been interpreted in some circumstances to exclude contracts of insurance as a form of federal

¹⁷ See Chelsea Keenan, *After three years, Wellmark enters Iowa health insurance exchange with new plans, partners*, THE GAZETTE (Cedar Rapids, IA), May 12, 2016, <http://www.thegazette.com/subject/life/health/health-insurance/after-three-years-wellmark-enters-iowa-health-insurance-exchange-with-new-plans-partners-20160512> (noting that Wellmark, in deciding to enter the Iowa Marketplace, was specifically aware that Iowa’s Marketplace had approximately 300 individuals requiring treatment for “hemophilia, cancer, high-risk pregnancies, diabetes, and morbid obesity”, among other high-cost conditions).

¹⁸ 42 U.S.C. § 18031(c)(1)(a); *see also* 45 C.F.R. § 156.225(b).

¹⁹ 45 C.F.R. § 156.200(e).

²⁰ 42 U.S.C. § 18116.

financial assistance.²¹ A contract of insurance that is federal financial assistance is any contract of insurance that is funded, entered into, administered, or guaranteed by the federal government. Thus, an insurance company in a Marketplace that receives federally-subsidized payments such as through premium tax credits is covered by Section 1557.

Prior to being notified by Wellmark that it would refuse to make its QHPs available to the Patient, the Patient had a Wellmark Marketplace plan. Wellmark has received Federal financial assistance through the ACA.

Section 1557 specifically references the enforcement mechanisms “provided for” and “available under” Title VI, Title IX, Section 504, and the Age Discrimination Act (“the Age Act”). Disparate impact claims are allowed under the civil rights statutes referenced by Section 1557.²² Because Section 1557 incorporates the enforcement mechanisms in those statutes, it too must be interpreted to provide for complaints brought on behalf of an individual, a class, or by a third party.

B. The Rehabilitation Act

The Rehabilitation Act prohibits programs and services which receive federal funds from discriminating against persons with disabilities.

No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.²³

Under regulations implementing Section 504, programs subject to the Rehabilitation Act may not “provide benefits or services in a manner that limits or has the effect of limiting the

²¹ Because “contracts of insurance” are not excluded in the statutory text of Section 504 [of the Rehabilitation Act] but in its regulations, there have been conflicting decisions about whether the regulations properly exclude it. *Compare Moore v. Sun Bank of North Florida*, 923 F.2d 1423, 1429-32 (11th Cir. 1991) (finding that because Section 504 did not expressly exclude contracts of insurance or guaranty, regulations containing the exclusion were invalid as inconsistent with congressional intent and that the contract at issue did in fact constitute federal financial assistance) with *Gallagher v. Croghan Colonial Bank*, 89 F.3d 275 (6th Cir. 1996) (holding that based on the Section 504 regulation’s exclusion of contracts of insurance or guaranty as federal financial assistance, a bank’s receipt of reimbursement for default loans was not federal financial assistance and thus the bank was not subject to the Rehabilitation Act).

²² Dep’t of Justice, Title VI Legal Manual (2001), http://www.justice.gov/crt/about/cor/coord/vi_manual.php#B (stating that Title VI regulations “may validly prohibit practices having a disparate impact on protected groups, even if the actions or practices are not intentionally discriminatory”) (citing *Guardians Ass’n v. Civil Serv. Comm’n*, 463 U.S. 582, 582 (1983) and *Alexander v. Choate*, 469 U.S. 287, 293 (1985)); Dep’t of Justice, Title IX Legal Manual (2001), <http://www.justice.gov/crt/about/cor/coord/ixlegal.php#2> (citing cases and stating “[i]n furtherance of [Congress’] broad delegation of authority [to implement Title IX’s prohibition of sex discrimination], federal agencies have uniformly implemented Title IX in a manner that incorporates and applies the disparate impact theory of discrimination.”).

²³ 29 U.S.C § 794(a).

participation of qualified persons with disabilities.”²⁴

Persons living with hemophilia fall within the definition of “disabled” under regulations implementing the Rehabilitation Act, where disability is defined as:

1. A physical or mental impairment that substantially limits one or more of the major life activities of such individual;
2. A record of such an impairment; or
3. Being regarded as having such an impairment.²⁵

Wellmark’s 2016 decision to “carve out” the county of the Patient’s residence from the area in which it offered its QHPs is a clear violation of the Rehabilitation Act because Wellmark chose to “exclude” the Patient based on his physical impairment from being able to participate in its QHP offerings.

II. Wellmark’s Withdrawal from the Iowa Marketplace Discriminates Against Protected Health Conditions Under ACA

Wellmark’s decision to withdraw from the Iowa Marketplace was motivated by and has resulted in unlawful discrimination against patients with hemophilia, particularly the 17-year old Patient with hemophilia identified by Wellmark. Wellmark’s disclosure of the Patient’s condition and costs and Wellmark’s decision not to sell policies to individuals with hemophilia has resulted in other insurers withdrawing from the Marketplace, limiting the coverage options available to Iowans with chronic health conditions. As a health care policy research associate at Duke University recently noted, “[e]veryone is trying to avoid the \$12 million man.”²⁶

Wellmark, despite withdrawing from the Iowa Marketplace, continues to sell “grandmothered” (non ACA-compliant) plans in the state.²⁷ By remaining in the “grandmothered” market while exiting the ACA Marketplace, Wellmark has segmented the Iowa private insurance market. Wellmark is cherry-picking the most profitable customers, and leaving people who have chronic health needs with few or no affordable insurance options. As a result of Wellmark’s decision to withdraw, Iowans seeking health insurance in Iowa’s Marketplace only have one statewide insurer to choose from, Medica, which has announced it would have to raise premiums by an average of 43.5% in order to afford the risk it will incur due to all other insurers withdrawing.²⁸

²⁴ 45 C.F.R. § 84.52(a)(iv).

²⁵ 45 C.F.R. § 84.52(a)(iv). *See also* 29 C.F.R. § 1630.2(g).

²⁶ Jon Greenberg, *Is Iowa Obamacare’s canary in the coal mine? Not really.*, POLITIFACT, May 24, 2017, at <http://www.politifact.com/truth-o-meter/article/2017/may/24/iowa-obamacares-canary-coal-mine/>.

²⁷ *See* Olga Khazan, *Why So Many Insurers Are Leaving Obamacare*, THE ATLANTIC, May 11, 2017, at <https://www.theatlantic.com/health/archive/2017/05/why-so-many-insurers-are-leaving-obamacare/526137/>; *Wellmark announces 2018 individual ACA market decision in Iowa*, April 3, 2017, at <https://www.wellmark.com/about/newsroom/2017/04/03/2018-aca-market-decision>.

²⁸ Tony Leys, *Medica intends to stay in Iowa’s health-insurance market, at 43% higher price*, THE DES MOINES REGISTER, Jun. 20, 2017, at <http://www.desmoinesregister.com/story/news/health/2017/06/19/medica-intends-stay-iowas-health-insurance-market-43-higher-price/408694001/>.

III. Wellmark Impermissibly Disclosed Personal Health Information

HIPAA provides consumers with important privacy rights and protections with respect to their health information, including important controls over how their health information is used and disclosed by health plans.²⁹ OCR is charged with enforcing the protections and provisions of the HIPAA Privacy and Security Rules.³⁰ Under the Privacy Rule, a health plan, such as Wellmark, is a covered entity and must not disclose protected health information (“PHI”) absent express authorization from the individual or for a recognized purpose relating to treatment, payment or health care operation.³¹

In a speech to the Des Moines Iowa Rotary Club on March 30, 2017, Laura Jackson, Wellmark’s Executive Vice President for Health Care Innovation & Business Development, stated that Wellmark was providing health insurance coverage to a “17-year-old hemophiliac” patient at a cost of \$1 million a month. More than 100 people attended the Rotary meeting and the disclosure was widely published throughout the media, including The Des Moines Register and national publications, such as the Los Angeles Times.³² In disclosing this individual’s age, gender, and specific diagnosis in the context of business in Iowa, Wellmark effectively revealed the Patient’s PHI for the purpose of commercial gain, *i.e.* to improve its own business reputation.

In May 2016, Wellmark issued notices to plan members that it planned to “raise premiums by 38 percent to 43 percent” for 2017 in large part due to the costs of providing care to one patient who is receiving \$1 million per month worth of care for a severe genetic disorder.³³ In 2017 Wellmark announced it would exit this same Iowa market.

The March 2017 statement by Wellmark is an impermissible disclosure of PHI that can reasonably be used to identify an individual. It is a clear violation of HIPAA. It not only provides information that can be used to identify an individual, but also impermissibly reveals the name of the individual’s health insurance plan, *i.e.*, who pays for the individual’s medical expenses, and financial information about the payments being made on behalf of the individual. These “data points” are clearly categorized by OCR as protected health information.³⁴ Such a violation is more egregious when it is done for commercial gain. OCR should investigate this violation and impose the maximum penalties permitted under HIPAA.

²⁹ 42 U.S.C. § 300gg and § 1320d et seq. and 29 U.S.C. §1181.

³⁰ 45 C.F.R. Part 160 and Part 164, Subparts A and E.

³¹ 45 C.F.R. §§ 160.102, 160.103, and 164.

³² Laura Jackson, Executive Vice President Executive Vice President for Health Care Innovation & Business Development at Wellmark, Address at the Rotary Club of Des Moines IA (March 30, 2017), <https://portal.clubrunner.ca/1637/Stories/laura-jackson-wellmark>. The calendar date for the speech is available at: <https://portal.clubrunner.ca/1637/Events/Calendar> (click “March 2017”). *See also* Tony Leys, *Iowa teen’s \$1 million-per-month illness is no longer a secret*, THE DES MOINES REGISTER, May 31, 2017, <http://www.desmoinesregister.com/story/news/health/2017/05/31/hemophilia-patient-costing-iowa-insurer-1-million-per-month/356179001/>; Michael Hiltzik, *This one unbelievably expensive Iowa patient makes the case for single-payer healthcare*, L.A. TIMES, Apr. 24, 2017, <http://www.latimes.com/business/hiltzik/la-fi-hiltzik-iowa-20170424-story.html>.

³³ *See* Tony Leys, *Wellmark plans 38% to 43% increase for some customers*, THE DES MOINES REGISTER, May 12, 2016, <http://www.desmoinesregister.com/story/news/health/2016/05/12/wellmark-plans-38-to-43-increases-some-customers/84277758/>.

³⁴ *See* 45 CFR §§ 160.103 and 164.514.

RELIEF REQUESTED

The National Hemophilia Foundation, Hemophilia Federation of America, and Hemophilia of Iowa request that OCR:

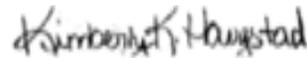
1. Review the basis for Wellmark's decision, including statements made by Wellmark executives which cited ACA requirements that QHP provide coverage to hemophilia patients, to withdraw from the Iowa Marketplace;
2. Take all necessary steps to remedy the unlawful conduct of Wellmark, including a corrective action plan and targeted outreach to and enrollment of people living with hemophilia;
3. Review Wellmark's public unauthorized disclosure of patients' health information, including the March 30, 2017 disclosure of a patient with hemophilia, for violations of HIPAA; and
4. Seek civil monetary penalties against Wellmark for non-compliance with federal civil rights protections.

The National Hemophilia Foundation, Hemophilia Federation of America, and Hemophilia of Iowa urge OCR to investigate discriminatory QHP offerings in Iowa, and elsewhere, as expeditiously as possible. We are available to offer any assistance necessary to ensure that people living with hemophilia get full access to the health benefits provided under the law.

Respectfully submitted,



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