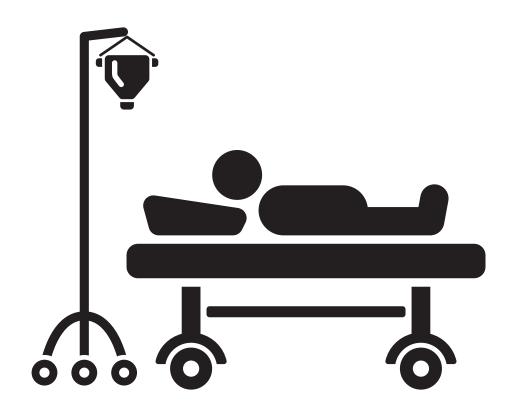
SICK, SCARED and SEPARATED from LOVED ONES II:

PROGRESS AND PROBLEMS IN HOSPITALS DISCLOSING THE PATIENT'S RIGHT TO CHOOSE WHO CAN VISIT



_____ *A Report by* _____

NEW YORKERS FOR PATIENT & FAMILY EMPOWERMENT NEW YORK PUBLIC INTEREST RESEARCH GROUP LAMBDA LEGAL

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EXECUTIVE SUMMARY

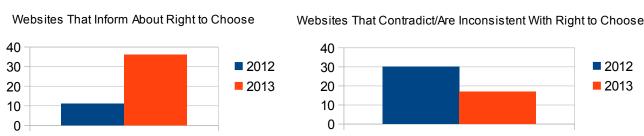
In 2007, Lisa Pond succumbed to a fatal brain aneurysm after being hospitalized in Miami, Florida. The hospital had denied Janice Langbehn, Ms. Pond's partner of 18 years and parent to their four children, the right to remain at her bedside—even though she had power of attorney—because it did not consider her to be "family." In response, President Obama instructed the Department of Health and Human Services' Centers for Medicare and Medicaid Services to issue a rule requiring hospitals to inform patients that they have the right to choose who can visit. New York has a fairly comparable rule. The patient's right to choose is very significant for families sometimes seen as "nontraditional."

The flexibility to choose who visits is also very important for elderly people. A 2010 report found that one out of every seven hospitalized Medicare beneficiaries is seriously harmed during care, and at least 44% of the injuries could have been prevented. In many cases, a family member may not be nearby to help. One-third of older Americans live alone, and it is estimated that up to 19% of New York seniors are socially or geographically isolated.

Many New Yorkers remain unaware that hospitals cannot limit a patient's visitors to "immediate family" unless the patient so wishes. Even when a hospital directly informs the patient of this rule by providing the legally required written statement about visiting rights, a patient who is ill may not read or fully grasp its meaning, or may not have it at hand if a hospital employee or volunteer is failing to follow the rule. An online statement can inform the patient's support people, including those who would have to travel to visit, of the patient's rights, while a wrongly restrictive online statement could inhibit visitation.

This report is a follow-up to a 2012 report, in which New Yorkers for Patient & Family Empowerment and the New York Public Interest Research Group examined the website-posted visiting policies for acute care hospitals in New York with 200 or more "staffed beds." The 2012 report found that many of these hospital websites contained language that directly conflicted with the patient's legal right to decide who may visit at his or her bedside. In March 2013, the two organizations were joined by Lambda Legal, a legal advocacy organization, in urging hospitals, by written correspondence, to come into compliance.

This report finds that more than one-third of the hospitals targeted in 2012 have since improved their website statements regarding the patient's right to choose visitors. Unfortunately, 17% of the hospitals examined still have language on their websites that directly conflicts with or is inconsistent with the federal rule, and only 36% of the websites examined affirmatively inform viewers of this important right.



All hospitals in New York should immediately remove erroneous language on their websites that conflict with the federal and New York State regulations, and they should do more than just not run afoul of these rules. To ensure full, consistent communication and implementation of the rules, all hospitals should post on their websites language that clearly discloses the patient's right to choose visitors. Compliance with the letter and the spirit of this important requirement will help ensure that every hospital patient has the support of a trusted companion, if the patient so desires, at the times when such support is most needed.

INTRODUCTION

A person who is admitted to a hospital often has to struggle to maintain a sense of dignity and self-determination. Hospital patients often feel as though they are losing control over their lives. Strangers come into the room at all hours of the day and night, giving them instructions and warnings that they may or may not fully understand, poking and prodding them, and sticking them with needles to extract blood or inject them with fluids or medications. They may be asked to agree to a test or treatment, but "ask" is often too mild a word to describe the encounter; it often feels much more like a high-pressure demand. It is a disorienting experience even when hospital staff do their best to be compassionate.

In addition to lifting spirits, visits from loved ones and friends can help patients monitor their own care, understand instructions, ask questions about treatments, and prevent prescription errors and other medical mistakes or negligence. The Joint Commission ("TJC"), which accredits hospitals based on medical and safety standards, urges patients to ask a trusted person "to be your advocate" and "stay with you, even overnight" at the hospital to "help make sure you get the correct medicines and treatments."

This assistance is important. Little has changed since the Institute of Medicine's disturbing 1999 report, *To Err Is Human*, which found that the number of Americans dying each year from medical errors was roughly equivalent to the downing of one jumbo jet each day.² The U.S. Department of Health & Human Services Inspector General's 2010 report found that one out of every seven hospitalized Medicare beneficiaries is seriously harmed during their care, and at least 44% of these events are preventable.³

One indignity that some hospital patients have experienced is a restriction on who can visit when the patient is in the intensive care unit ("ICU") or other specialized care unit. In the past, a long-held tradition of restricting visitation for patients under intensive care to "immediate family only" had the adverse effect of depriving some patients of the support of a caring friend or loved one. Both the federal government and New York State's Department of Health have adopted regulations designed to keep the patient's door open to visitors of their own choosing. Under these rules, which recognize that patients have the right to choose who can visit when visitation is restricted, the patient – not the hospital – decides who will be at the patient's side when the patient is most in need of caring support.

Unfortunately, many people do not know that the old "immediate family only" policy has been deemed invalid, and hospitals must do more to correct this problem. In 2012, New Yorkers for Patient & Family Empowerment and the New York Public Interest Research Group examined the website-posted visiting policies for the 99 large acute care hospitals in New York State (defined for the purposes of this review as those with 200 or more "staffed beds") in a report entitled, *Sick, Scared and Separated from Loved Ones*. Among that report's findings were widespread violations of the federal and New York State rules regarding a patient's right to choose visitors.

This report is a follow-up to that 2012 website review. It finds significant improvement in the number of large hospitals' websites that are fully consistent with the federal and New York State rules on a patient's right to choose visitors since the 2012 review. Unfortunately, too many of the hospital websites examined still contain visiting policy statements that conflict with the patient's legal right to choose priority visitors whether or not they are members of the patient's "immediate family." Other websites

¹The Joint Commission, "Help Prevent Errors in Your Care" (an educational brochure for the public), *available at* www.jointcommission.org/assets/1/6/speakup.pdf, downloaded July 25, 2013.

²Institute of Medicine, "To Err Is Human: Building a Safer health System" (Nov. 1999), *available at* http://www.iom.edu/~/media/Files/Report%20Files/1999/To-Err-is-Human/To%20Err%20is%20Human%201999%20%20report%20brief.pdf.

³Department of Health & Human Services Office of Inspector general, "Adverse Events in Hospitals: National Incidence Among Medicare Beneficiaries" (Nov. 2010), at ii, *available at* http://oig.hhs.gov/oei/reports/oei-06-09-00090.pdf.

exhibit a persistent failure to disclose this important right to the public. This report therefore urges that the New York State Department of Health reach out to all hospitals in New York and guide them into full compliance and cooperation with this important federal and New York State policy.

I. BACKGROUND AND METHODS

A. Background: The Federal and State Rules on Patients' Rights That Invalidate Hospital "Immediate Family Only" Visiting Policies

In 2009, *The New York Times* profiled the story of a woman named Lisa Pond, who had been hospitalized at Jackson Memorial in Miami, Florida with a brain aneurysm. The *New York Times* explained that Janice Langbehn, Ms. Pond's life-partner for 18 years and parent of their four adopted children, who also had power of attorney, was denied the right to be at Ms. Pond's bedside because the hospital did not consider Ms. Langbehn to be "family." Over a period of eight hours, Ms. Langbehn was only allowed one five-minute visit with Ms. Pond in the hospital's trauma area while a priest administered last rites. Later she was let in, but Ms. Pond was unconscious and died the next morning. The story garnered the attention of President Obama, who issued a Presidential Memorandum instructing his health secretary to establish rules to recognize the right of hospital patients to choose their visitors, having noted that this would also allow a patient with no spouse or child to have the support and comfort of a good friend.

In response to this Presidential Memorandum, the Centers for Medicare & Medicaid Services ("CMS") of the U.S. Department of Health and Human Services ("HHS") issued new rules on November 10, 2010, requiring any hospital that cares for Medicare or Medicaid patients to establish a written policy that gives patients control over who may be present at their bedside. The rules became effective on January 18, 2011. Under these rules, such hospitals must:

- Establish their visiting policies and procedures in writing;
- State in writing the reasons for any clinically necessary or reasonable restriction or limitation on visitation rights; and
- Inform each patient of the visitation rights and, in particular, the patient's right to receive visitors that he or she approves, and to deny persons visitation access.⁷

More specifically, it states that any hospital receiving Medicaid or Medicare funding must:

⁴Tara Parker-Pope, "Kept from a Dying Partner's Bedside," *New York* Times, May 19, 2009, at D5. Ms. Langbehn was a client of Lambda Legal. Information on her case and the subsequent advocacy work by Lambda Legal on behalf of establishing the new federal regulations on visiting rights can be viewed at http://www.lambdalegal.org/incourt/cases/langbehn-v-jackson-memorial.

⁵President Barack Obama, "Presidential Memorandum – Hospital Visitation: Memorandum for the Secretary of Health and Human Services" (Apr. 15, 2010), *available at* <u>www.whitehouse.gov/the-press-office/presidential-memorandum-hospital-visitation</u>.

⁶Sheryl Gay Stolberg, "Obama Widens Medical Rights for Gay Partners," *New York Times*, Apr. 15, 2010, at A1. ⁷42 CFR §§ 482 and 485 (2010). The public notice of adoption of these rules, with responses to public comments, was published in 75 *Fed. Reg.* 70831 (Nov. 19, 2010).

Inform each patient (or support person, where appropriate) of the right, subject to his or her consent, to receive the visitors whom he or she designates, including, but not limited to, a spouse, a domestic partner (including a same-sex domestic partner), another family member, or a friend, and his or her right to withdraw or deny such consent at any time.⁸

Such hospitals must also "Ensure that all visitors enjoy full and equal visitation privileges consistent with patient preferences." In the press release issuing the rules, HHS Secretary Kathleen Sebelius states, "Basic human rights – such as your ability to choose your own support system in a time of need – must not be checked at the door of America's hospitals." Thus, the regulations require that all hospitals inform patients (or their representatives) of this right, and establish that all patients are guaranteed the right to designate who may and may not visit them.

New York State had taken significant steps in this direction even before the federal rule was issued. Public Health Law § 2805-q states, "No domestic partner shall be denied any rights of visitation of his or her domestic partner when such rights are accorded to spouses and next-of-kin at any hospital, nursing home or health care facility." The New York State law became effective June 1, 2010. Further, the New York State Department of Health regulation that sets out the "Patient's Bill of Rights" — which was amended after passage of Public Health Law § 2805-q — is relatively consistent with the federal rule in that it refers to "other adults" rather than only domestic partners. Under this regulation, no patient should be called upon to prove that a priority visitor is a domestic partner, and the patient should also be deemed free to designate close friends, trusted personal care aides or spiritual counselors as priority visitors.

Having this flexibility to choose someone other than a family member, domestic partner or "significant other" is particularly important for elderly people. Recent demographics show that fully one-third of all older Americans live alone. ¹² Moreover, the National Council on Aging reports that up to 19% of New York State's seniors live in social or geographic isolation, without the immediate support from a spouse or family member. ¹³ The message about their right to have a support person of their own choosing should be consistent and very clear.

People rejected by their families due to their sexual orientation or gender identity constitute another population particularly in need of visitation enforcement, as they are likely to form "families of choice" rather than blood kinship. Additionally, gay people often have fewer legally sanctioned family structures available to them, due to discrimination int he laws of various jurisdictions. Elderly lesbian, gay, bisexual or transgender people may be doubly at-risk when visitation rights are disregarded, as "an

⁸⁴² CFR § 482.13(h)(2); see also § 485.635(f)(2).

⁹42 CFR § 482.13(h)(4); *see also* § 485.635(f)(4). The notice of adoption of the rule stated, in response to public comments, that this "condition of participation" in Medicare and Medicaid for hospitals "applies to all patients, regardless of their payment source." 75 Fed. Reg. 70831, 70835 (Nov. 19, 2010).

¹⁰Centers for Medicare & Medicaid Services, U.S. Department of Health & Human Services, Press Release, "Medicare Finalizes New Rules to Require Equal Visitation Rights for All Hospital Patients" (Nov. 17, 2010), *available at* http://www.hhs.gov/news/press/2010pres/11/20101117a.html.

¹¹10 NYCRR § 405.7 (effective Dec. 22, 2010).

¹²E. Klinenberg, S. Torres and E. Portacolone, "Aging Alone in America: A Briefing Paper Prepared for the Council on Contemporary Families for Older Americans Month," May 2012, *available at*

http://contemporaryfamilies.org/images/stories/Aging_Alone_Klinenberg_Torres_Portacolone_CCF_Brief_May_2012.pdf); Maggie Fox, "Report Shows More Older Americans Living Alone," *National Journal* (May 1, 2012), http://www.nationaljournal.com/healthcare/report-shows-more-older-americans-living-alone-20120501.

¹³National Council on Aging, *Crossing New Frontiers: Benefits Access Among Isolated Seniors* (May 2011), p. 7, available at http://www.ncoa.org/assets/files/pdf/center-for-benefits/crossing-new-frontiers.pdf.

increasing number of studies show that caregiving is often undertaken by friends, neighbors, and other community members, rather than by biological or legal family members."¹⁴

While it is possible that many hospitals may inform patients orally about the right to choose priority visitors, this is not enough to comply with the modern rule. The federal rule appropriately emphasizes that visiting policies *must be in writing*, and hospitals must provide patients with a clearly written statement about their right to choose who can visit.¹⁵ Of course, even if a hospital provides patients with a written "hard copy" of a visiting policy that discloses the patient's right to choose visitors, posting contrary language on the hospital's website – or language implying that the hospital may restrict the patient's visitors to "family only" – contravenes the regulation and is confusing and misleading.¹⁶ Whether online, in written "hard copy" or in oral conversation, any communication to patients about the hospital's visiting policy should clearly and consistently reflect current law on patients' visitation rights.

This examination of 99 large hospitals' websites reveals that several still have language that directly conflicts with the federal and New York State rules regarding the patient's right to choose visitors, and that most of these websites still do not disclose the existence of this important right.

B. Methodology for Review of Hospital Websites

In 2012, researchers from Patient & Family and the New York Public Interest Research Group ("NYPIRG") examined the websites of 99 hospitals as part of the inquiry that resulted in issuance of their joint report entitled *Sick, Scared and Separated from Loved Ones: A Report on NYS Hospital Visiting Policies and How Patient-Centered Approaches Can Promote Wellness and Safer Healthcare* (August 2012). That review focused on New York's "acute care" hospitals – facilities that provide inpatient medical care and related services for surgery, acute medical conditions or injuries (usually for a short-term illness or condition) – having 200 or more staffed beds.¹⁷

The 2012 report found that 30% of the hospital websites made public statements contrary to or inconsistent with the New York State and federal regulations, with 23 hospitals claiming to limit certain types or times of visitation to "immediate family," "close family" or "family" and three others adding only the category of "significant other." The remainder had website language implying that certain visitation was restricted to family by, for example, stating where "family" could wait during surgery.

¹⁴AnnaMuraco & Karen Fredriksen-Goldsen, "'That's What Friends Do': Informal Caregiving for Chronically III Midlife and Older Lesbian, Gay and Bisexual Adults, *J of Social & Personal Relationships* 28:1073, 1073-74 (2011), *available at* http://caringandaging.org/wordpress/wp-content/uploads/2013/04/Thats-wht-firends-do-Informal-caregiving-for-chronically-ill-midlife-and-older-LGB-adults.pdf.

¹⁵42 CFR § 482.13(h); *See also* § 485.635(f). The notice of adoption of the rule stated, in response to public comments, that, while they are not requiring the facility to provide the notice of rights in any particular format, it must be a "written notice," consistent with the notice of rights provisions of 42 CFR §491.13(a). 75 *Fed. Reg.* 70831, 70834 (Nov. 19, 2010).

¹⁶Also, family members and loved ones may not have ready access to hand-outs provided directly to the patient upon admission, so posting legally appropriate and accurate information on the website is important.

¹⁷The Montefiore Medical Center's locations at Moses Hospital, Weiler Hospital and North Hospital were treated as three branches of the same facility because of ownership, relationship, and the consistency of their visiting policies with each other. St. Luke's Hospital and Roosevelt Hospital were treated as two branches of the same facility under the Continuum Health Partners corporation, as they share senior leadership and their visiting policies were consistent with each other. (While Beth Israel is also part of the Continuum Health Partners corporation, it has separate senior leadership.) In contrast, while the New York Presbyterian Hospital website gave the impression that visiting hours at its Columbia University Medical Center and Weill Cornell facility were identical, the facilities stated different visiting policies when questioned, so they were treated as separate facilities for the purposes of the 2012 report and, for consistency, will continue to be so treated in this report.

The report also found that only 11 hospitals had taken the initiative on their websites to inform viewers that patients have the right – including at times when visitation is restricted for clinical reasons – to select visitors regardless of family affiliation.

As a follow-up measure, in March 2013, Patient & Family worked with Lambda Legal and NYPIRG to revisit the hospital websites that previously had been identified as having language inconsistent with the federal and state policies regarding a patient's right to choose who can be with them when visitation is limited for clinical reasons. The organizations discovered at that time that, of the 30 websites that originally had been found to have language inconsistent with the federal and New York State rules, only four had removed all inconsistent language.

Patient & Family, Lambda Legal and NYPIRG then sent a letter on or about March 14, 2013, to each of the 22 hospitals that still had improper language in their online visiting policies, requesting that they update their websites to remove the inconsistencies with federal and New York State regulations.¹⁸

Four months later, in July 2013, a third review of these websites was conducted. The results of that review form the basis for this report.

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¹⁸See Appendix F for a template of this letter.

II. FINDINGS

Many of New York's acute care hospitals with 200 or more staffed beds have modified their websites to comply fully with the letter and the spirit of the federal and New York State rules, clearly disclosing the patient's right to choose who can visit. This is important because if a hospital staff person or volunteer wrongly asserts that visitation is limited to "family only," the patient or visitor may be able to find the correct information online to help advocate for the patient's right to choose. Other hospitals, unfortunately, still make statements on their websites that directly conflict with the patient's right to choose visitors. Still others simply fail to inform the public about this important right.

On a positive note, this report finds that **more than one-third** of the hospital websites originally reviewed in July 2012 – 35 out of 99 – have improved their communications about the patient's right to choose (as of July 25, 2013).¹⁹

> Eleven hospitals that previously had posted language on their websites that conflicted or implied a conflict with the patient's right to choose have eliminated that language and now positively and clearly state the patient's right to choose visitors:²⁰

> > Community-General Hospital of Greater Syracuse Forest Hills Hospital (Queens) Long Island Jewish Medical Center (New Hyde Park) Mercy Medical Center (Rockville Centre) North Shore University Hospital (Manhasset) Plainview Hospital St. Elizabeth Medical Center (Utica) Samaritan Medical Center (Watertown) Saratoga Hospital (Saratoga Springs) Upstate University Hospital (SUNY) at Syracuse Vassar Brothers Medical Center (Poughkeepsie)

Fifteen hospitals that had previously been silent regarding the patient's right to choose visitors have added new language that clearly communicates the patient's right:

> Albany Medical Center Arnot Ogden Medical Center (Elmira) Cayuga Medical Center at Ithaca Highland Hospital (Rochester) **Huntington Hospital** Interfaith Hospital (Brooklyn) John T. Mather Mem. Hosp. (Pt. Jefferson) Winthrop-University Hospital (Mineola) Lenox Hill Hospital (Manhattan)

Memorial Sloan-Kettering Cancer Center (Manhattan) NY-Presbyterian Hosp./Columbia Med Ctr (Manhattan) NY-Presbyterian Hosp./Weill Cornell (Manhattan) St. Charles Hospital (Port Jefferson) United Health Serv. Wilson Med. Center (Johnson City) Westchester Medical Center (Valhalla)

Eight hospitals have removed statements that improperly restricted visitation but, as of July 25, 2013, still have either failed to disclose the patient's right to choose visitors or have failed to remove language that implies or states a restriction contrary to that right:

> Brookhaven Memorial Hospital (Patchogue) Good Samaritan Regional Medical Center (Suffern) Kings County Hospital Center (Brooklyn) Lutheran Medical Center (Brooklyn) Mercy Hospital of Buffalo St. Francis Hospital (Roslyn) St. Luke's Roosevelt Hospital (Manhattan) Wyckoff Heights Medical Center (Brooklyn)

¹⁹See Appendix D.

²⁰Franklin Hospital (Valley Stream) is also among these, but had left outdated language stating a restriction contrary to the patient's right to choose on a relatively inaccessible old webpage that is now being deleted.

A. Hospital Websites That Make Public Statements Directly Contrary to or Are Inconsistent With the Patient's Right to Choose Visitors

Of the hospital websites reviewed, 17% (17 out of 99) make public statements that are either contrary to or inconsistent with the New York State and federal policies. This compares with 30% (30 out of 99) making such contrary or inconsistent statements last year – a compliance improvement of 43% in this area.

Eight hospital websites, as of July 25, 2013, remain particularly problematic because their websites contain language expressly purporting to limit certain types or times of visitation to "immediate family," "close family," "family" or "family members and significant others," and they contain no language stating the patient's right to choose visitors. These hospitals are:²¹

Crouse Hospital (Syracuse) Elmhurst Hospital Center (Queens) Jamaica Hospital Medical Center (Queens) Unity Hospital of Rochester

Phelps Memorial Hospital Center (Sleepy Hollow) Rochester General Hospital St. John's Riverside Hospital (Yonkers) Stony Brook University Medical Center

One of these facilities, Rochester General Hospital, restricts visiting to immediate family members and a "significant other" (connoting a romantic relationship) in intensive care, but fails to state that a patient could choose someone else, such as a close friend, trusted personal care aide or spiritual counselor.²² While the reference to "significant other" adds some flexibility, it is not enough to comply with the federal and state rules.

Five other hospital websites use language that strongly implies a restriction on non-family visitors by designating where "family members" can wait while a patient is in the ICU or surgery, or specifying visiting hours for "family members."²³ The misleading language is not countered by any language declaring clearly the patient's right to choose visitors. These hospitals are:

> Beth Israel Medical Center (Manhattan) Champlain Valley Physicians Hospital Medical Center (Plattsburgh) Good Samaritan Regional Medical Center (Suffern) Hospital for Special Surgery (Manhattan) St. Luke's Roosevelt Hospital (Manhattan)

Three additional hospitals have statements posted on their websites to inform patients and visitors that patients have the right to choose who can visit them (regardless of family affiliation), but their online visiting policies still contain some outdated language that conflicts with this right, stating that visits to the ICU are restricted to "immediate family only" or "family only." These are:

> Long Island College Hospital (SUNY Downstate Medical Center)(Brooklyn) St. Francis Hospital (Roslyn) Sound Shore Medical Center of Westchester (New Rochelle)

In addition, Franklin Hospital (Valley Stream) had unintentionally left outdated language on a relatively inaccessible old webpage, unlikely to be accessed by an ordinary internet search, that is now being deleted.

²¹Links for these hospitals' visiting policy statements are contained in Appendix A.

²²See Appendix A.

²³Links for these hospitals' visiting policy statements are contained in Appendix A. See, e.g., Beth Israel Medical Center webpage on "Surgery," under "Visitors" heading, which states, "During your surgery, family members may relax in the surgical waiting room" (http://wehealny.org/patients/BI home/BI InpatientSurgery.html#forms, downloaded July 25, 2013).

²⁴Links for these hospitals' visiting policy statements are contained in Appendix A.

B. Hospital Websites That Comply With and Inform Patients and Visitors of the Patient's Right to Choose Visitors

Of the hospital websites reviewed, **36%** (**36 out of 99**) now provide public information clearly stating that patients have the right to choose who can visit them (with no restrictions on family affiliation). This compares with only 11% (11 out of 99) making such properly informative statements last year – an improvement of 69% in this area. In other words, the number of large hospitals in New York whose websites fully comply with the federal and New York State legal requirements and clearly disclose that visitation is based on the patient's choice has more than tripled since 2012.

The hospitals with fully compliant and informative websites,²⁵ making it clear that visitation rights are based on the patient's choice, are:

Albany Medical Center

Arnot Ogden Medical Center (Elmira)

Cayuga Medical Center at Ithaca Community-General Hospital of Greater Syracuse

Forest Hills Hospital

Glen Cove Hospital Glens Falls Hospital

Highland Hospital (Rochester)

Huntington Hospital

Interfaith Medical Center (Brooklyn)

John T. Mather Memorial Hospital (Port Jefferson)

Kingsbrook Jewish Medical Center (Brooklyn)

Lenox Hill Hospital (Manhattan)

Long Island Jewish Med. Ctr (New Hyde Park)

Memorial Sloan-Kettering Cancer Center (Manh.) Mercy Medical Center (Rockville Centre)

Metropolitan Hospital Center (Manhattan)

Montefiore Medical Center (Bronx)

Nassau University Medical Center (East Meadow)

New York-Presbyterian Hosp./Columbia Medical Center

New York-Presbyterian Hosp./Weill Cornell

NYU Langone Medical Center (Manhattan)

North Shore University Hospital (Manhasset)

Plainview Hospital

St. Charles Hospital (Port Jefferson)

St. Elizabeth Medical Center (Utica)

St. Joseph's Hospital (Elmira)

St. Peter's Hospital (Albany)

Samaritan Medical Center (Watertown)

Saratoga Hospital (Saratoga Springs)

Strong Memorial Hospital (Rochester)

United Health Services Wilson Med. Center (Johnson City)

Upstate University Hospital (SUNY) at Syracuse

Vassar Brothers Medical Center (Poughkeepsie)

Westchester Medical Center (Valhalla) Winthrop-University Hospital (Mineola)

Seventeen of these – Cayuga Medical Center at Ithaca, Forest Hills Hospital, Glen Cove Hospital, Glens Falls Hospital, Huntington Hospital, Lenox Hill Hospital, Long Island Jewish Medical Center, Mercy Medical Center, Metropolitan Hospital Center, Nassau University Medical Center, NYU Langone Medical Center, North Shore University Hospital, Plainview Hospital, Saratoga Hospital, United Health Services Wilson Medical Center, Westchester Medical Center and Winthrop-University Hospital – also include in their website-posted visiting policies a nondiscrimination clause that bars discrimination with regard to visitation based on sexual orientation or gender identity, or specifically include reference to visitation by a "same-sex domestic partner."

Franklin Hospital (Valley Stream) also contained compliant language to this effect on its new website at the time that this review was conducted, and – with the deletion of the unintentionally remaining and relatively inaccessible old webpage containing noncompliant language – will be added to this list.

²⁵Links for these hospitals' visiting policy statements are contained in Appendix B. Note: The websites of Arnot Ogden Medical Center and St. Joseph's Hospital (Elmira) state, "It is our pleasure to support our patients in their choice of visitors." Montefiore Medical Center's website states that in the intensive/special care units, not only immediate family members but also "other persons with a close relationship with the patient" may visit. The Vassar Brothers Medical Center's website states, "VBMC recognizes the importance of family support during hospitalization – and we recognize that "family" may mean any individual who plays a significant role in a person's life." These statements are probably adequate to counter an erroneous attempt to bar a non-family visitor of the patient's choosing, but the websites could more directly explain that the patient has the right to choose who can visit. *See* links in Appendix B.

C. Hospital Websites That Do Not Disclose the Patient's Right to Choose Visitors

The remaining 46% (46 out of 99) of the hospitals' websites do not disclose the patient's right to select who can visit when visitation is limited, 26 and most of them are completely silent on the matter. These hospital websites contain no language that directly contravenes New York State or federal policies, but nontheless fail to notify the public on their visiting policy webpage about the patient's right to choose priority visitors. The large hospitals that have not disclosed on their websites the patient's right to choose visitors, as of July 25, 2013, are:

Bellevue Hospital Center (Manhattan) Bronx-Lebanon Hospital Center Brookdale Hospital Medical Center (Brooklyn) Brookhaven Memorial Hospital (Patchogue) Brooklyn Hospital Center, Downtown Campus **Buffalo General Medical Center** Coney Island Hospital (Brooklyn) Ellis Hospital (Schenectady) Erie County Medical Center (Buffalo) Faxton-St. Luke's Healthcare (Utica) Flushing Hospital Medical Center (Queens) Good Samaritan Hospital Medical Ctr (West Islip) Harlem Hospital Center (Manhattan) Jacobi Medical Center (Bronx) Kings County Medical Center (Brooklyn) Lawrence Hospital Center (Bronxville) Lincoln Medical & Mental Health Center (Bronx) Lourdes Hospital (Binghamton) Lutheran Medical Center (Brooklyn) Maimonides Medical Center (Brooklyn) Mercy Hospital of Buffalo Mount Sinai Medical Center (Manhattan) New York Hospital Queens (Flushing, Queens)

New York Methodist Hospital (Brooklyn) North Central Bronx Hospital Northern Westchester Hospital (Mount Kisco) **Nyack Hospital** Orange Regional Medical Center (Goshen) Queens Hospital Center (Jamaica, Queens) Richmond Univ. Medical Center (Staten Island) St. Barnabas Hospital (Bronx) St. Catherine of Siena Medical Center (Smithtown) St. Francis Hospital (Poughkeepsie) St. John's Episcopal Hospital at South Shore (Far Rockaway) St. Joseph Hospital (Bethpage) St. Joseph's Hospital Health Center (Syracuse) St. Luke's Cornwall Hospital (Newburgh) Samaritan Hospital (Troy) Sisters of Charity Hospital (Buffalo) South Nassau Communities Hospital (Oceanside) Southside Hospital (Bay Shore) Staten Island University Hospital - North Shore LIJ²⁷ University Hospital of Brooklyn (SUNY Downstate) White Plains Hospital Center

Woodhull Medical and Mental Health Center (Brooklyn)

Wyckoff Heights Medical Center (Brooklyn)

These hospitals may be taking other actions in compliance with the rules. The federal rule requires them to inform patients in writing of the patient's right to choose visitors. The important question of whether or not hospitals are handing patients, upon admission, outdated patient guidance booklets, brochures or factsheets that include language that contravenes the new requirements is beyond the scope of this report, but should be reviewed by the Department of Health. It is also somewhat helpful that all hospitals are required to give patients a written copy of the "Patients' Bill of Rights," established by the New York State Department of Health, within which is listed, as item number 18, the patient's right to "Authorize those family members and other adults who will be given priority to visit consistent with your ability to receive visitors." (By referring to "family members and other adults" rather than "family members or other adults," this provision does not communicate as clearly as possible that when visitation is restricted, the patient may choose a family member or other trusted person.) Hospitals should do more, however, to ensure that the federal and New York State rules are fully and consistently implemented.

²⁹10 NYCRR § 405.7 (effective date Dec. 22, 2010).

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²⁶Links for these hospitals' visiting policies are contained in Appendix C. Coney Island Hospital, Harlem Hospital and Kings County Hospital have language on their websites that indicates significant flexibility but does not clearly disclose that visitation privilege and priority is based on the patient's right to choose.

²⁷The official name of this hospital is now "North Shore LIJ – Staten Island University Hospital" – but since it is commonly known as Staten Island University Hospital, it is listed in this report as Staten Island University Hospital – North Shore LIJ so that interested readers may more easily find it.

²⁸St. Joseph Hospital (Bethpage), for example, provides patients with a "Patient Guide" that states that "all visitors chosen by the patient...can enjoy full and equal visitation privileges consistent with the wishes of the patient or his or her representative." See its "Patient Guide" (2012) (provided as a "hard copy" hand-out to patients upon admittance to the hospital), p. 11, compared with the hospital's minimal website-posted information on visitation at www.stjosephhospitalny.org/directions/ (downloaded July 25, 2013).

Providing incoming patients with a handed-out booklet or flier that informs them of their right to choose visitors is important for compliance with the regulation. Nevertheless, it is still very important to provide this information clearly in the hospital's online visiting policy even if the website contains no language directly contrary to the rule. Any written statement of the hospital's visiting policy should include the patient's right to choose visitors. While the federal rule does not directly require that people other than the patient or support person be notified of the patient's right to choose visitors, or that the notice be posted within the hospital.³⁰ failing to provide such notice on the hospital's website could have significant impacts. Indeed, a prospective visitor who has the mistaken impression that the out-dated restriction on visiting in intensive care or special care units to "immediate family only" is still in effect may be discouraged by a hospital's misleading or uninformative online visiting policy statement and may not try to visit the hospital, especially if significant travel is involved or if the patient's ability to reach out or communicate with potential support people is limited. Also, as noted above, a visitor at a hospital who is wrongly barred from seeing a patient who has, or would have if given the chance, stated a preference to see that visitor is unlikely to have ready access to such a hand-out and may not know that the hospital's action is improper. Finally, as noted above, patients who are sick may not read or fully grasp the meaning of a document provided in the hospital. If family and other trusted persons are informed about the policy, they can discuss it with the patient and help make arrangements for the patient to have better support while in the hospital.

CONCLUSION

Substantial progress has been made since last year's review of the websites of these 99 large acute care hospitals in New York State. More of these hospital websites now comply with the letter and the spirit of the federal and state rules regarding the patient's right to choose who can visit (especially when visitation is restricted for clinical reasons). Nevertheless, several hospitals still have conflicting or inconsistent language on their websites, and many hospitals do not disclose in their online visiting policy statements the patient's right to choose who can visit. The New York State Department of Health, in its oversight capacity, should reach out to all hospitals statewide and guide them into full compliance and cooperation with this important federal and New York State policy.

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³⁰42 CFR § 482.13(h). The notice of adoption of the rule stated, in response to public comments, that, "Providing each patient or support person with the written notice of visitation rights before the start of care sufficiently achieves the goal of informing patients; therefore, we are not requiring such notice to be posted within the facility.... Furthermore, we are not requiring facilities to provide the notice of rights in any particular format or to individuals other than the patient or support person." 75 *Fed. Reg.* 70831, 70834 (Nov. 19, 2010).