

President Barack Obama
The White House
1600 Pennsylvania Avenue NW
Washington DC 20500

February 26, 2009

2009 legislation

Improved administrative oversight and legislative review of Office for Civil Rights

Dear President Obama,

Enclosed please find documentation demonstrating loss of correspondence and confusion involving OCR employees, including Director Winston Wilkinson's executive office, concerning a June 26, 2006 grievance involving a HIPAA violation.

This complaint involves the Kaiser Hospital Ombudsman accepting a nonlegitimate Medical Directive without verifying its authenticity, and released my dying daughter's medical information to this individual. As a result, my daughter, a cancer patient, suffered needlessly as her medical care was affected as this individual caused havoc in the hospital. The motivation of this individual was to obtain my daughter's \$928K estate she received from a malpractice arbitration.

The loss of correspondence and inability of employees to send the grievance to the correct department in a timely matter, resulted in OCR refusing to review this complaint due to the 180 day limit as stated in the Privacy Rule at C.F.R. §160.306(b)(3). This law also states, "*the 180 day filing requirement may be waived if an individual has been actively pursuing other administrative remedies,*" which I was easily able to prove. Enclosed is a news article where I met with officials of the DMHC and Business Transportation and Housing Agency and discussed the issues concerning this grievance. Although these agencies did not complete their investigations concerning this grievance until well into 2007, Marilou King J.D., Senior Advisor, HIPAA Privacy Compliance and Enforcement, and Michael Kruey, Regional Manager OCR Region IX, refused to comply with the Privacy Law, instead blaming me for not complying with the 180 day time limit. They only seemed interested in defending their employees negligent actions

This negligent work ethic resonated all the way to OCR Director Wilkinson's executive office. Since 7/28/08, all correspondence faxed and mailed was "lost" three times. Kathryn Hoppi from the Office of Congressional Liaison (202-690-6786) who tried to intervene on my behalf also experienced the frustration of loss of documents from Mr. Wilkinson's office.

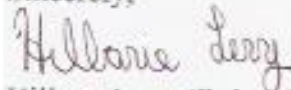
I have also not yet received a response from another concern contained in the 6/28/06 grievance, "*1/04 Kaiser policy of placing cancer patients at a low priority for blood transfusions*" According to Principal Deputy Director Robinsue Frohbose, it is under separate consideration by the San Francisco Regional Office. I have not received a response in over two years.

Please note, I am not requesting assistance for my personal matter, instead, I am providing this information as an example for this necessary legislation.

Improving administrative oversight and legislative review must be a priority as victims should not be forced to face the negative consequences caused by incompetent OCR employees. My daughter, as well as many other vulnerable patients deserves the dignity, respect and protection resulting from a fair investigation by OCR.

Thank you in advance for your attention to this matter.

Sincerely,



Hillarie Levy (Robyn Libitsky's mother)

2958 Chippewa Avenue

Simi Valley, CA 93063-2015

805-522-5188

Hillarie643@aol.com



1-18-06

Centers for Medicare and Medicaid Services

June 25, 2006

To whom this may concern,

The enclosed article by the LA Times, made me compelled to contact this agency.

The serious problems described in the article mirror the continuing problems regarding Kaiser cancer patients, another group of very ill and expensive patients. My daughter, who passed away from cancer on 2/15/05, experienced, these horrific incidents. Although not on medicare or Medicaid, she was the exception. As my daughter received chemo treatments, sometimes on a daily basis, I observed these issues also occurring toward the mostly elderly cancer patients. Kaiser's motivation is financial gain.

The enclosed article (to locate several other articles regarding my fight, search me on Google) explaining my 4/17/06 visit to Sacramento where I was successful in making changes where Kaiser must include the arbitration award when reporting the information to the State, forcing Kaiser to end their practice of not reporting all responsible Doctors, also includes other issues facing cancer patients:

- (1) 1/04 policy of placing cancer patients on a low priority for blood transfusions.
- (2) Requesting organ donation from ineligible cancer patients
- (3) Inappropriately promoting Hospice care
- (4) Lack of humane treatment (mental and physical abuse by Doctors nurses and technicians
- (5) Ombudsman's lack of knowledge in determining false and legitimate documentation

Unfortunately, according to DMHC's 6/8/06 correspondence, the reason for their refusal to correct these horrific problems is because they "found no systemic violations on these issues." Identifying "systemic violations" as a prerequisite to take action and correct issues, as your dept. has discovered, is ineffective. After all, LA Times discovered the Kaiser kidney patient problems while the DMHC had no clue this was occurring, as they were waiting around for "systemic violations!"

On 7/12/06, I will meet with Edward Heidig, Deputy Secretary and General Counsel of the Business, Transportation and Housing Agency to further discuss how to correct these issues. I am also enlisting your aid to help prevent these cancer patients, like the kidney patients, from needlessly suffering and dying.

Sincerely,

Hillary Levy

Hillarie Levy (Robyn Libitsky's mother)
2958 Chippewa Avenue
Simi Valley, Calif. 93063
Hillarie643@aol.com
805-522-5188

* This letter included
large amount of documents
which were all lost

26)



DEPARTMENT OF HEALTH & HUMAN SERVICES
CENTERS FOR MEDICARE & MEDICAID SERVICES
WESTERN CONSORTIUM
DIVISION OF SURVEY AND CERTIFICATION

August 2, 2006

Hillarie Levy
2958 Chippewa Avenue
Simi Valley, CA 93063

Dear Ms. Levy:

This is in response to your letter of June 25, 2006 regarding issues with Kaiser. Let me first offer my condolences on the loss of your daughter.

Unfortunately, the article you discuss is not enclosed for our review and I am not sure if the article would provide specific information needed in order to conduct a complaint survey of a facility. However, if you send us specific information regarding your complaints, the Centers for Medicare and Medicaid Services (CMS) can look into these allegations and assign them for investigation.

Thank you for your interest in the Medicare beneficiary community, especially during what I can only imagine must have been a most difficult and stressful time in your life.

If you have any questions, please contact Diane Greif, of my staff, at (415) 744-2831.

Sincerely,

Deborah Greif, Acting for

Deborah Romero, Manager
Hospital & Community Care Operations Branch
Division of Survey and Certification, CMS

* Response to my June 25, 2006 letter. I resent the documents which they lost on Aug 7, 2006.

595671
 Regn. to ~~Public~~ PSC
 (~~done~~) 7/24/06
 Rosanna

Staff Action Desktop - [Staff Action - Folder (Queries) - 595671]
 Folder Administration Reports Window Help

Cover Sheet | Synopsis | Assignment List | Documents | Status | Notes

General Information

Folder Queue: CES/RUS Transfer | Folder Type: General Public | Scannet [1]: [118] | Scannet's Due Date: [118]

Description: LEVY, HILLARIE | Members of Congress: [118] | Scannet's Reference No.: [118]

Action, Suspense, and Priority

Action: [] | Action Office: SAN FRANCISCO RO(RD)G | Notification: Notify me when folder is done

Priority: DM/G en Pub/Busk Mail | Due Date & Time: 21-Aug-2006 08:00 PM | Method of Notification: []

Correspondence Information

Communication Type: Letter | Correspondent [1]: [118] | Addressee [10] [1]: [118]

Date of Communication: 25-Jun-2006 | Letter Count: []

Receive Date: 11-Jul-2006

Refresh records 1 to 5 | 24-Jul-2006 10:00 AM | Staff Action Desktop | 4 Microsoft Office Word | 10:00 AM

Computer print out included with the Aug 2, 2006 letter demonstrating my complaint was in their system on 7/29/06

12A



STATE OF CALIFORNIA
DEPARTMENT OF MANAGED HEALTH CARE

August 1, 2006

Hillarie Levy
2958 Chippewa Avenue
Simi Valley, CA 93063

Dear Ms. Levy

Thank you for your continuing commitment to improving patient care in California. As discussed in our meeting of July 12th, the Department of Managed Health Care (DMHC) is moving forward with several specific actions related to Kaiser. As you know, DMHC staff have researched complaint records related to each of the following five issues you raised to look for patterns of problems in the care received by other Kaiser patients:

- 1) Humane treatment;
- 2) Ombudsman knowledge level;
- 3) Enlisting organs from cancer patients for donation;
- 4) Inadequately explaining the meaning of Hospice care to cancer patients;
- 5) Cancer patient transfusion priority.

No systemic violations on these issues were found in our records. However, our Enforcement Office is following up on individual cases to research them further. We are continuing to investigate other aspects of the issues that you raised and will monitor the issues as the DMHC moves forward with the following steps regarding quality of care:

1. The DMHC has embarked on a system-wide review of Kaiser's quality of care. This is a non-routine, focused review of the quality of care at Kaiser. I have asked our staff to include the Kaiser Woodland Hills Hospital where your daughter was hospitalized. At Woodland Hills I have asked that our staff specifically examine the treatment of cancer patients. It will be several months before this thorough review is completed. The final report will become a public document and will be posted on our Web site.
2. DMHC staff is also looking into the issue of recruitment of cancer patients as organ donors as a part of our current investigation of Kaiser transplant issues.

All issues concerning the OCR grievance were being actively investigated by MHC well into 2007

ARNOLD SCHWARZENEGGER
GOVERNOR

BUSINESS,
TRANSPORTATION
AND HOUSING
AGENCY

980 9th Street
Suite 500
Sacramento, CA 95814-2728
916-324-8176 Voice
916-322-9430 Fax

320 West 4th Street
Suite 880
Los Angeles, CA 90013-1105
213-620-2744 Voice
213-574-7183 Fax

LUCINDA A. FENES
DIRECTOR

WWW.HMOHELP.CA.GOV
1-888-HMO-3319

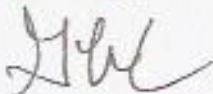
August 1, 2000

Page 2

3. Regarding hospice care, we are enforcing the law that requires Kaiser to appropriately offer hospice services throughout the state. We want to hear concerns from the public on the issues related to hospice care, and will be conducting a public meeting on hospice issues in the near future. The date will be posted on our Web site.

It is deeply regrettable what you and your family went through with the death of your daughter, Robyn. We appreciate your bringing these important issues to our attention, and your dedication to ensuring that California HMO patients receive high quality care.

Sincerely,



G. Lewis Chartrand
Chief Deputy Director

GLC:HH/jb

Simi woman speaks before Senate

FROM PAGE 1 —

Committee and from there to the Assembly for its approval.

"We expect it to pass," Barbosa said, pointing out that the bill has the backing of both Democrats and Republicans since it passed the bipartisan committee.

If the bill makes it to the governor for his signature, Levy wants to be present when he officially makes it law.

The same day she spoke to the committee, Levy met with Lew Chartrand, chief deputy director of the Department of Managed Health Care (DMHC), and Edward Heidig, deputy secretary of the Business, Transportation and Housing Agency, the umbrella state organization that oversees the DMHC.

Levy said they talked about other disturbing issues that surfaced during Robin's treatment at Kaiser. Levy alleged the hospital's ombudsman couldn't differentiate between legitimate and false legal documents and criticized the hospital's policies of placing cancer patients on a low priority for blood transfusions, requesting organ donation from ineligible cancer patients and inappropriately promoting hospice care.

A Kaiser spokesman did not respond to questions by press time.

Lynne Randolph, a DMHC spokeswoman, wouldn't comment specifically on what Heidig and Chartrand plan to do about Levy's charges, citing state laws regarding personal health matters.

"We'll be responding to (Levy) through correspondence on those four points," she said.

All issues concerning the grievance were investigated well in to 2007

(3)

Simi woman speaks before Senate committee

By Michelle Knight
knight@shin.com

Hillarie Levy doesn't give up. The outspoken Simi Valley mother refused to give up hope for her daughter, Robin Libitsky, who died from a rare form of cancer in 2005 at the age of 29.

And Levy never quit looking for a way to hold accountable all six Kaiser doctors who allegedly misdiagnosed Robin. Levy's efforts may now be paying off. Last week, Levy urged a state

Senate committee to pass SB 1438, which would require medical providers to

report every doctor named in an arbitration award to the state medical board for inclusion on their website.

By law, the medical board must make public the names and licenses of doctors against whom an arbitration award is granted.



Hillarie Levy and Robin Libitsky

Levy told the bipartisan Business, Professions and Economic Development

Committee that, although Robin won nearly \$1 million in a 2002 award against Kaiser and six of its physicians, only one doctor was reported to the medical board.

"It made it clear it wasn't for me anymore," Levy said of her testimony in Sacramento. "It's not going to save Robin. These are problems that are happening to everyone. This affects everyone."

Sen. Liz Figueroa (D-Fresno) is the author of SB 1438. Figueroa also sponsored the initial law.

"Our view is that this was the case all along," said Jeff Barbosa, a spokesman for Figueroa. "But the bill does clarify it so it can't be misinterpreted."

After Levy testified, the Senate committee unanimously passed SB 1438. The bill now goes to the Senate Appropriations

— PAGE 5B PAGE 2

makers
rate milestone
— Page 10
e that mom

Local arrested
in vehicular
manslaughter

Honoring those lost in the Holocaust



Director
Office for Civil Rights
Washington, D.C. 20201

APR 26 2007

The Honorable Elton Gallegly
Member, U.S. House of Representatives
2829 Townsgate Road, #315
Thousand Oaks, CA 91361
Attn: Paula Sheil

Transaction Number: 07-65910

Dear Congressman Gallegly:

Thank you for your letter on behalf of your constituent, Ms. Hillarie Levy, concerning the health information privacy regulation (Privacy Rule) issued pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The Office for Civil Rights (OCR) is responsible for interpreting and enforcing the Privacy Rule. Your constituent has questions about a complaint that was not accepted for investigation by the OCR San Francisco Regional Office because it was not timely filed. Ms. Levy disagrees with OCR's decision not to accept her case for investigation and asked that your office intervene on her behalf.

OCR is committed to ensuring that every complaint is appropriately resolved, and thus we have decided to conduct a review of the case. We will communicate directly with Ms. Levy once this review of her case has been completed. We note that Ms. Levy also filed a civil rights discrimination complaint with the OCR San Francisco Regional Office, and that matter is still under separate consideration by the regional office.

We trust that this information is helpful to you. Please let me know if we can be of further assistance.

Sincerely,

Robinsue Frohboese, J.D., Ph.D.
Principal Deputy Director

cc: Michael Kruley
Regional Manager
OCR Region IX
Attn: Bob Abad Santos

I or
Congressman Gallegly
Office never heard from
Ms. Frohboese again
and I never heard from
the San Francisco Regional
Office regarding my discrimination
complaint - Kaiser policy of placing
cancer patients at a lower priority
to be heard than others.

(2)

July 28, 2008

Office for Civil Rights
US Department of Health and Human Services
200 Independence Ave., SW, Room 515 F
Washington DC 20201
Attention: Winston Wilkinson Esq., Director
202-619-3437

Transaction Number: 07-65910

Large packet was mailed with
this cover letter but like in done
2006, my information was lost again!

August 22
Page 2

Dear Mr. Wilkinson,

Enclosed please find Principal Deputy Director, Robinsuc Frohboese's April 26, 2007 correspondence addressed to Congressman Gallegly, where she promised to respond directly to me once the review of my case was completed. Not only did Dr. Frohbose fail to fulfill her written promise to the Congressman, all inquiries from the Congressman's office were ignored!

Only when I sent the enclosed July 17, 2008 correspondence to Dr. Frohboese did I receive on July 28, 2008, the enclosed June 6, 2007 correspondence from Marilou King. It was clear the only information Ms. King attempted to review was the 2/5/07 and 5/4/07 OCR closure letters.

This issue concerns a refusal by OCR to review my case involving HIPAA violations occurring as my daughter lay at Kaiser Hospital, dying of cancer. I had requested a waiver, which according to OCR, would be granted for good cause shown. Kaiser's internal grievance process was completed on April 19, 2006. I filed my initial complaint with OCR on June 25, 2006, immediately after learning this issue involved OCR, after reading a LA Times news article. The 67 days was well within the 180 day timeframe OCR requires!

I have enclosed my June 25, 2006 correspondence as well as the August 2, 2006 response from Deborah Romero, Manager, Hospital & Community Operations Branch, Division of Survey and Certification CMS, acknowledging receipt of my complaint along with informing me, OCR lost all but my letter. She even sent me a copy of the front of the envelope I used to send OCR, showing the June 26 mailing date and five stamps, demonstrating the large amount of documents I had provided, as well as OCR case entry forms confirming June 25, 2006 as the date of receipt.

As suggested by Diane Greif, via phone, from the same department, I resent OCR the documentation on August 7, 2006. According to Ms. King, my complaint was not filed until November 1, 2006. I can not be responsible for the loss and delay Ms. Romero's division took to distribute my information to the correct OCR department.

It must also be noted, during the time I filed the June 25, 2006 complaint with OCR, other administrative remedies were actively being pursued with DMHC, Department of Business Housing and Transportation, the Governor, Senator Deborah Oritz, senator George Runner, and Senator Liz Figueroa, which ended well into 2007. (enclosed news article) Not one of these legislators or state agencies informed me that this part of my complaint involved OCR! If they are unaware of OCR's realm of enforcement, how am I expected to know!

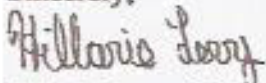
This letter was lost by
[unclear] and all

Since I have clearly proven my fulfillment of the requirements for actively pursuing other administrative remedies, 1) filed 67 days after the Kaiser internal grievance, 2) immediately after learning of OCR through an LA Times article, filed the June 25, 2006 complaint, 3) during this time I was actively pursuing administrative remedies with several state agencies and legislators, warrant this waiver. To refuse this request is in violation of the privacy rule.

I have one more request. Could you please look into another complaint filed in the same June 25th letter, "*1/04 Kaiser policy of placing cancer patients at a low priority for blood transfusions*," which Dr. Frohboese notes is under separate consideration by the San Francisco Regional Office. I have not yet received any response in over two years.

Thank you in advance for reviewing my enclosed documents instead of relying on the inaccurate correspondence of your colleagues. My daughter, as well as many other vulnerable patients, deserve the dignity and respect and the protection resulting from a fair investigation by OCR.

Sincerely,



Hillarie Levy (Robyn Libitsky's mother)
2958 Chippewa Avenue
Simi Valley, CA 93063
805-522-5188

Office for Civil Rights
U.S. Department of Health and Human Services
22 Independence Ave., SW, Room 515F
Washington DC 20201
Attention: Winston Wilkinson Esq., Director
202-619-3818

September 2, 2008
Pages: 3

Transaction Number: 07-65910

It was again brought to my attention by your Intern, this 9/2/08 fax was also lost. I am resending it in hopes it you finally receive it

Hillarie Levy
9/9/08 pages: 3

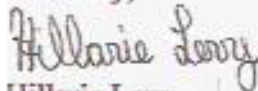
Dear Mr. Wilkinson,

Enclosed please find the correspondence mailed on July 28, 2008. On August 22, 2008, a male Intern assigned to answering phones, informed me the correspondence as well as the large amount of information accompanying it was lost. He instructed me to fax the cover letter and he would call me back immediately to assure me it had been received. According to today's phone conversation with a female Intern, who put me on hold three times, there is no record of it. I am again sending the cover letter in hopes it does not get lost again.

This constant loss of correspondence and confusion, is a perfect example of why my grievance concerning a violation of HIPAA, filed June 25, 2006, which was lost, and the proper department did not receive the replacement I again sent until 11/06, causing OCR to refuse to review my case on the basis of being over 160 days, makes valid my reason for contacting you.

Hopefully this latest example helps you understand the frustration victims of violations of their Civil Rights have, as we must also be forced to deal with consequences by incompetent OCR employees.

Sincerely,



Hillarie Levy
2958 Chippewa Avenue
Simi Valley, CA 93063
805-522-5188

*
I tried so hard to send these letters but OCR always lost them



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

November 4, 2008

Director
Office for Civil Rights
Washington, D.C. 20201

Ms. Hillarie Levy
2958 Chippewa Avenue
Simi Valley, California 93063-2015

Transaction Number: 07-68738

Dear Ms. Levy:

I am responding to the facsimiles that you have sent to me recently, as well as your facsimile to Assistant Secretary for Legislation Vince Ventimiglia, dated October 3, 2008, about the complaints you filed with the Office for Civil Rights (OCR), Department of Health and Human Services (HHS), alleging violations of the HIPAA Privacy Rule and Federal civil rights disability protections. I have personally examined your case and, at the outset, I want to offer my sincere condolences on the loss of your daughter.

Upon receipt of your October 23, 2008, facsimile to me and based on the referral from Assistant Secretary Ventimiglia of your October 3, 2008, facsimile to him, I asked both my Deputy Director for Health Information Privacy and my Deputy Director for Civil Rights to re-examine your complaints and our regional and headquarters' actions in response to them to ensure that we were giving your concerns our highest level of attention.

With regard to your complaint alleging HIPAA Privacy Rule violations, my senior staff conducted a formal re-consideration last year of our regional office's decision and, in a letter dated June 6, 2007, advised you that we affirmed our regional office's decision. In reaching this decision, we carefully re-examined your original complaint and the information you enclosed with both your request for reconsideration and your other correspondence. My staff also has had many conversations with you to discuss your concerns and explain the basis of our decision. In reviewing your Privacy Rule complaint multiple times in the past and re-examining it now, it is evident that our regional and headquarters' decisions are consistent with the provisions of the Privacy Rule.

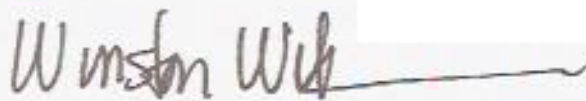
With regard to your civil rights complaint, you allege that in January 2004, Kaiser Permanente discriminated against cancer patients on the basis of disability by implementing a policy that placed cancer patients on a lower priority for blood transfusions. Our regional office did not receive your complaint concerning this January 2004 matter until December 13, 2006, well beyond the 180-day period for filing a timely complaint with OCR, and for that reason did not undertake an investigation of your

Page 2

complaint. In your October 23, 2008, letter you state that you never received a response from our regional office regarding the disposition of this complaint. In a letter dated May 4, 2007, our regional office notified you of its decision that the complaint was untimely filed but did not provide you with written notice of your opportunity for reconsideration. As such, we will conduct a headquarters' review of this Kaiser policy at issue and the related decisions of the California Department of Managed Health Care (DMHC) that previously reviewed your complaint concerning this Kaiser policy, and others, as appropriate.

A representative of my Civil Rights Division staff, Ms. Karmen Todd, will be in contact with you in the coming week to obtain a copy of relevant documents in your possession that will facilitate and expedite our review of this matter. We appreciate your continued cooperation and assistance.

Sincerely,



Winston Wilkinson

cc: Vince Ventimiglia
Assistant Secretary for Legislation

Mike Kruley
Regional Manager
Region IX

200 Independence Avenue., SW, Room 515 F
Washington DC 20201
Attention: Winston Wilkinson Esq., Director

Transaction Number: 07-65910

Dear Mr. Wilkinson,

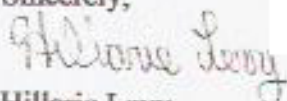
Thank you for your 11/04/08 correspondence.

I continue to remain confused as to why OCR continues to refuse to review my complaint concerning HIPAA Privacy Rule violations. Although as stated in your letter, "*your senior staff carefully re-examined my original complaint along with having many conversations with me to discuss my concerns and explain the basis of OCR's decision,*" your staff consistently failed to answer my questions!

According to Senior Advisor, Marilou M. King J.D., "*under the Privacy Rule at 45 C.F.R. § 160.306(b)(3) the 180 day filing requirement may be waived if an individual has been actively pursuing other administrative remedies.*" I have enclosed correspondence from DMHC involving their investigation of the HIPAA and blood transfusion issues, ending 8/22/07, well past the time OCR lost, then four months later on 11/1/06, sent my complaint to the correct department! Under the Privacy Rule, I was well within the timeframe for OCR to accept and conduct an investigation. Perhaps your staff can explain why their miscalculation of nine months is consistent with the provisions of the Privacy Rule. Prior to this I was told by your staff of their decision, while always refusing to answer this question!

Another question which remains unanswered by your staff is; Why are victims of civil rights refused a fair investigation if their documents are lost/misplaced by OCR staff? Since I have clear and concise evidence my June 25, 2006 grievance was not only received but documented in computer data before being lost, an answer, not denial or excuse, is much appreciated.

Sincerely,



Hillarie Levy
2958 Chippewa Avenue
Simi Valley, CA 93063
805-522-5188

cc. Congressman Pete Stark