

# COMMISSION TO STUDY DIFFICULT-TO-PLACE PATIENTS

## MEETING AGENDA

Monday, October 26, 2015

Room 216, Cross State Office Building, Augusta

- 12:00 p.m. Welcome and introductions  
*Commission Chairs*
- 12:15 p.m. Overview of Resolve 2015, Chapter 44 (LD 155) and summary of background  
enacting legislation  
*Commission Staff*
- 12:30 p.m. Briefings on:
- Barriers that exist for placement of patients with complex medical and mental health conditions;
  - Facilities where these patients are currently placed and issues faced by these facilities; and
  - Potential options for increasing the availability of residential care and long term care facilities for specialized patient populations that are difficult to place for care.
- Jeff Austin, Maine Hospital Association;*  
*Richard Erb, Maine Health Care Association;*  
*Brenda Gallant, Long-Term Care Ombudsman; and*  
*Simonne Maline, Consumer Council System of Maine*
- 1:30 p.m. Commission discussion
- 2:20 p.m. Future meetings planning
- 2:30 p.m. Public comment opportunity
- 3:00 p.m. Adjourn

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# Commission to Study Difficult-to-Place Patients

Resolve 2015, c. 44

Thursday, October 16, 2015

## Appointment(s) by the Governor

### **Jeffrey A. Austin**

Maine Hospital Association  
33 Fuller Road  
Augusta, ME 04330

An individual representing a statewide association of hospitals

### **Melvin Clarrage**

221 Longfellow St., Unit 2  
Westbrook, ME 04092

An individual representing an organization promoting independent living for individuals with disabilities

### **Richard A. Erb**

35 Melden Drive  
Brunswick, ME 04011

An individual representing a statewide association of long-term care facilities

### **Brenda C. Gallant**

Long-Term Care Ombudsman  
61 Winthrop Street  
Augusta, ME 04330

Director of the long-term care ombudsman program (MRS Title 22, Section 5106, subsection 11-C)

### **Michael Lemieux**

Seaside Healthcare  
850 Baxter Blvd.  
Portland, ME 04103

An individual or a family member of an individual with a complex medical condition

### **Simonne Maline**

Consumer Council System of ME  
55 Middle St., Suite 2  
Augusta, ME 04330

An individual representing statewide organization advocating for people with mental illness

### **Kim Moody**

24 Stone Street, Suite 204  
Augusta, ME 04330

An individual representing an organization that represents people with disabilities

## Appointment(s) by the President

### **Sen. Roger J. Katz – Chair**

3 Westview Street  
Augusta, ME 04330

Senate members from each of the two parties holding the largest number of seats in the legislature

### **Sen. Anne M. Haskell**

31 Higgins Street  
Portland, ME 04103

Senate members from each of the two parties holding the largest number of seats in the legislature

**Appointment(s) by the Speaker**

**Rep. Andrew M. Gattine - Chair**

529 Stroudwater Street  
Westbrook, ME 04092

Members of the House of Representatives  
from each of the two parties holding the  
largest number of seats in the legislature

**Rep. Richard Malaby**

52 Cross Road  
Hancock, ME 04640

Members of the House of Representatives  
from each of the two parties holding the  
largest number of seats in the legislature

**Rep. Peter C. Stuckey**

20 Vaill Street  
Portland, ME 04103

Members of the House of Representatives  
from each of the two parties holding the  
largest number of seats in the legislature

**Commissioner, Department of Health and Human Services**

Ricker Hamilton  
11 State House Station  
Augusta, ME 04333-0011

Commissioner of Health and Human  
Services or Commissioner's Designee

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**Staff:**

Dan Tartakoff  
Natalie Haynes  
Office of Policy and Legal Analysis

STATE OF MAINE

IN THE YEAR OF OUR LORD  
TWO THOUSAND AND FIFTEEN

H.P. 113 - L.D. 155

**Resolve, To Establish the Commission To Study Difficult-to-place Patients**

**Emergency preamble.** Whereas, acts and resolves of the Legislature do not become effective until 90 days after adjournment unless enacted as emergencies; and

**Whereas,** this resolve establishes the Commission To Study Difficult-to-place Patients to study certain issues related to difficult-to-place patients with complex medical conditions and the feasibility of making policy changes to the long-term care system for those patients; and

**Whereas,** immediate enactment of this resolve is necessary to provide the commission adequate time to complete its work; and

**Whereas,** in the judgment of the Legislature, these facts create an emergency within the meaning of the Constitution of Maine and require the following legislation as immediately necessary for the preservation of the public peace, health and safety; now, therefore, be it,

**Sec. 1. Commission established. Resolved:** That, notwithstanding Joint Rule 353, the Commission To Study Difficult-to-place Patients, referred to in this resolve as "the commission," is established; and be it further

**Sec. 2. Commission membership. Resolved:** That the commission consists of 13 members appointed as follows:

1. Two members of the Senate appointed by the President of the Senate, including members from each of the 2 parties holding the largest number of seats in the Legislature;
  2. Three members of the House of Representatives appointed by the Speaker of the House, including members from each of the 2 parties holding the largest number of seats in the Legislature;
  3. The Commissioner of Health and Human Services or the commissioner's designee;
- and

4. Seven members appointed by the Governor who possess expertise in the subject matter of the study, as follows:

- A. The director of the long-term care ombudsman program described under the Maine Revised Statutes, Title 22, section 5106, subsection 11-C;
- B. An individual representing a statewide association of long-term care facilities;
- C. An individual representing a statewide association of hospitals;
- D. An individual representing an organization that represents people with disabilities;
- E. An individual representing a statewide organization advocating for people with mental illness;
- F. An individual representing an organization promoting independent living for individuals with disabilities; and
- G. An individual or a family member of an individual with a complex medical condition; and be it further

**Sec. 3. Chairs; subcommittees. Resolved:** That the first-named Senate member is the Senate chair and the first-named House of Representatives member is the House chair of the commission. The chairs of the commission are authorized to establish subcommittees to work on the duties listed in section 5 and to assist the commission. Any subcommittees established by the chairs must be composed of members of the commission and interested persons who are not members of the commission and who volunteer to serve on the subcommittees without reimbursement. Interested persons may include individuals with expertise in placing individuals with complex medical conditions in long-term care placements, individuals who provide long-term care to individuals with complex medical conditions, individuals affected by neurodegenerative diseases and individuals affected by mental illness; and be it further

**Sec. 4. Appointments; convening of commission. Resolved:** That all appointments must be made no later than 30 days following the effective date of this resolve. The appointing authorities shall notify the Executive Director of the Legislative Council once all appointments have been completed. After appointment of all members and after adjournment of the First Regular Session of the 127th Legislature, the chairs shall call and convene the first meeting of the commission. If 30 days or more after the effective date of this resolve a majority of but not all appointments have been made, the chairs may request authority and the Legislative Council may grant authority for the commission to meet and conduct its business; and be it further

**Sec. 5. Duties. Resolved:** That the commission shall study the following issues and the feasibility of making policy changes to the long-term care system for patients with complex medical conditions:

- 1. Identification of categories of patients with complex medical and mental health conditions who are unable to be discharged from hospitals because there are no facilities or providers who are able to care for them or to accept them for care;

2. A description of how patients with complex medical and mental health conditions are placed currently, including the involvement of staff from the Department of Health and Human Services;

3. Identification of primary barriers to placement of patients with complex medical and mental health conditions currently;

4. A description of facilities in which patients with complex medical and mental health conditions are currently placed, including whether the facilities are in-state and the costs associated with the patients' care;

5. Options for increasing availability of residential care and long-term care facilities, including conversion of existing facilities such as hospitals, nursing homes and the Dorothea Dix Psychiatric Center to long-term care facilities for specialized populations that are difficult to place for care, such as ventilator-dependent patients, geropsychiatric patients and bariatric patients;

6. Rates of reimbursement necessary to operate facilities to manage patients with complex medical conditions, including psychiatric conditions and neurodegenerative diseases; and

7. Any other issue identified by the commission; and be it further

**Sec. 6. Staff assistance. Resolved:** That the Legislative Council shall provide necessary staffing services to the commission; and be it further

**Sec. 7. Information and assistance. Resolved:** That the Commissioner of Health and Human Services shall provide information and assistance to the commission as required for its duties; and be it further

**Sec. 8. Report. Resolved:** That, no later than December 2, 2015, the commission shall submit a report that includes its findings and recommendations, including suggested legislation, for presentation to the Joint Standing Committee on Health and Human Services.

**Emergency clause.** In view of the emergency cited in the preamble, this legislation takes effect when approved.





# 127th MAINE LEGISLATURE

## FIRST REGULAR SESSION-2015

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Legislative Document

No. 966

H.P. 665

House of Representatives, March 17, 2015

### An Act To Assist Patients in Need of Psychiatric Services

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Reference to the Committee on Health and Human Services suggested and ordered printed.

*Robert B. Hunt*

ROBERT B. HUNT  
Clerk

Presented by Representative MALABY of Hancock.

Cosponsored by Representatives: GATTINE of Westbrook, VACHON of Scarborough,

Senators: BRAKEY of Androscoggin, McCORMICK of Kennebec.



## OFFICE OF POLICY AND LEGAL ANALYSIS

Date: April 22, 2015

To: Joint Standing Committee on Health & Human Services

From: Anna Broome, Legislative Analyst

### **LD 155, An Act to Expand Housing Opportunities for Patients with Complex Medical Conditions**

#### **SUMMARY:**

#### **CONCEPT DRAFT SUMMARY**

This bill is a concept draft pursuant to Joint Rule 208. The purpose of this bill is to help ensure that patients with complex medical conditions who are in hospitals are placed in more appropriate nonhospital settings. The bill proposes to fund the ongoing costs associated with beds in nonhospital settings for:

1. Patients with severe brain injuries;
2. Bariatric patients;
3. Patients who are dependent on a ventilator for the long-term;
4. Young adult patients with substance abuse issues who receive extended intravenous therapy due to infections;
5. Young adult patients with spinal cord injuries;
6. Young adult patients who have had strokes;
7. Homeless patients who need preoperative care such as feeding tubes; and
8. Patients who are violent and have been previously discharged from a health care facility due to violence.

#### **TESTIMONY SUMMARY:**

##### **Proponents:**

- Pressing issue regarding individuals for whom adequate and sufficient long term care facilities do not currently exist in ME. Stuck in hospitals instead of appropriate settings.
- Hospitals not receiving payment once the acute medical need is addressed. Cannot discharge a patient to nowhere. Current practice is not fair to patients or hospitals.
- MHA – days awaiting placement survey (below). Snapshot – 119 patients awaiting

placement (43 for >40 days).

- EMHS – one hospital with 35 patients had 17 on extended stay unable to be discharged due to lack of community options. Hospitals told to call every facility in the state – repeatedly. Took a DRC complaint being filed to move a brain injured patient to an out of state facility.
- Private Duty Nursing Section 96 – can meet the medical requirements but also need to have a place of residence and family support to meet needs in the absence of nursing staff. Need to build on Section 96 with a housing option that includes a contingency for skilled care. Homes could house 3-6 residents with Sec. 96 available around the clock.
- LTC facilities not equipped, staffed or licensed to care for complex needs, e.g. ALS patients on a vent. Some choose not to vent and die rather than go out of state. Hope-JG Foundation’s vision is to build a 10 person ALS/MS residence.
- Money Follows the Person/Homeward Bound – largest struggle is finding housing.
- Alpha One – not just young people who need appropriate placements for substance abuse, spinal cord injury or strokes.
- LTC Ombudsman – experience that DHHS is willing to work on rate setting that reflects the acuity of individuals to facilitate admission to a ME nursing home.
- Need a larger discussion among DHHS, hospitals, doctors and LTC providers.

#### **ADDITIONAL INFORMATION NEEDED BY COMMITTEE:**

- MHA survey:
  - 29/36 hospitals responded. 93% indicated the problem has gotten worse in the last year.
  - 119 patients awaiting placement (42 for <10 days; 34 for 10-40 days; 43 for >40 days).
  - 34 waiting for NF bed; 23 for skilled NF bed; 15 for inpatient psych bed; 14 for dementia care – rest of the list in Jeff Austin’s testimony.
  - Reasons cited: 31 – no suitable bed at appropriate level of care available; 24 – special needs; 9 – facility of origin refused; 9 – behavioral issues; 9 – MaineCare process delays; 9 – other financial issues; 7 – guardianship process delays; 4 SNF needing NF bed following rehab.
- MaineHealth SNF rate for patient at MMC for two and a half years – a one-off reimbursement solution between the patient’s family and their insurance carrier. Patient no longer needed acute care but there was no facility in the state to take her because of her ventilator.
- Other questions attached from MaineHealth.
- Proposed rule that includes Ventilator Care Service – notice sent 4/8/15 (attached along with relevant sections of the proposed rule).

#### **FISCAL IMPACT:**

Not yet received from OFPR (concept draft).

LD155: Questions from Maine Medical Center

1. Does MaineHealth have any insight into why the dramatic increase of these cases over the last several years or months? That answer may identify other people/entities/groups that should be in the room for continued conversation of this bill and issue.

The general trends that MMC is seeing includes increased homelessness, increased percentage of patients receiving free care, increased geriatric psychiatry issues, and increased complications of IV drug use. Although the population of these patients is growing, the available beds in the community is not. Support for psychiatric patients in the community is decreasing and there are only 3 geropsych longterm care facilities in the State. Two other issues that factor in are the lack of a Long Term Acute Care Facility (LTAC) in the State of Maine and the lack of willingness of MaineCare to send patient's out of state for LTAC care.

2. Is there a figure that we can give the committee so they can base their decisions on how much it's actually costing our hospitals to keep these patients in house? It would help us decide options if we can grasp the fiscal ramifications of any possible solutions.

Back of the envelope estimate is \$9.1 million per year.

3. A number of years ago there was a CAC Report developed for the Criminal Justice and Safety Committee. It led to county jail consolidation. Included in that were patients with multiple disorders with both physical and mental health disorders. A process was put in place to formulate more specialized care. Some of these issues must be from the realization that the criminal justice system could no longer house people with persistent mental health issues. Can we find out how many of the patients in question may have been formally involved in the criminal justice system-specifically the patients who are violent and have been previously discharged from a health care facility due to violence?

No good data on this but anecdotally we have a handful of patients per year who are transferred to MMC from jail, end up having a serious and expensive medical problem who the jail decides to "furrow." In other words they release the patient so they are not responsible for the medical bill thus MMC not only gets reimbursed less but then is often saddled with a very difficult discharge.

4. To all: If we're hypothetically dealing with 100+ patients statewide and we had facilities for 6 people, which equals 20+ facilities each, how much would it cost to house the patients versus the inpatient costs now?

There is an approximately \$700 difference per patient between acute hospital and skilled or assisted living facility.

5. How many hospitals have either attached or local units which may already have the infrastructure to support a vent dependent unit or would be willing to create the unit if there were appropriate reimbursement available to care for them?

MMC does not feel that we have capacity to do this but there are several skilled facilities in the State, that either already have taken long term vent patients, or would be willing to do so if the reimbursement were such that they could adequately staff the patients. We estimate that number to be at least 6 skilled facilities.

**Rule-making Fact Sheet**  
5 M.R.S.A. § 8057-A

*Vent proposed rule*

**AGENCY:** Department of Health and Human Services, MaineCare Services  
Division of Policy

**NAME, ADDRESS, PHONE NUMBER OF AGENCY CONTACT PERSON:**

Elizabeth S. Bradshaw-Livingston, Comprehensive Health Planner II  
elizabeth.s.bradshaw@maine.gov  
MaineCare Services  
11 State House Station, 242 State Street, Augusta, Maine 04333-0011  
PHONE: (207) 624-4054 FAX: (207) 287-9369 TDD/TTY 711

**CHAPTER NUMBER AND RULE TITLE:** Chapter 101, MaineCare Benefits Manual,  
Chapters II & III, Section 67, Nursing Facility (NF) Services

**STATUTORY AUTHORITY:** 22 M.R.S.A. §§ 42, 3173; Public Law 2014, Chapter 582.

**DATE AND PLACE OF PUBLIC HEARING:**

Date: May 4, 2015  
Time: 10:00 am  
Location: 19 Union St., Rm. 110, Augusta, Maine 04333

The Department requests that any interested party requiring special arrangements to attend the hearing contact the agency person listed above before April 27, 2015.

**DEADLINE FOR COMMENTS:** Comments must be received by midnight, May 14, 2015

**PRINCIPAL REASON OR PURPOSE FOR PROPOSING THIS RULE:** This proposed rulemaking would: (1) provide a new methodology for calculating recapture of depreciation upon the sale of a nursing facility, and (2) add reimbursement for Ventilator Care Services as a separately reimbursable service (i.e., above and beyond the daily NF rate). The purpose of providing a new methodology for calculating recapture of depreciation upon the sale of a nursing facility is to comply with Public Law 2014, Chapter 582. The purpose of adding reimbursement for Ventilator Care Services as a separately reimbursable service is to ensure that nursing facilities may be reimbursed for members that need Ventilator Care Services. \*

**IDENTIFICATION OF PRIMARY SOURCE OF INFORMATION:** Public Law 2014, Chapter 582.

**ANALYSIS AND EXPECTED OPERATION OF THE RULE:** (1) The policy changes how credits are calculated when determining the amount of Depreciation Recapture a provider must pay the Department upon the sale of their facility. The change allows credits to be calculated from the time the owner first licensed the facility instead of when the asset was purchased. This will reduce the Provider's obligation for recapture in most instances. We also apply credits to moveable equipment which had previously been excluded from credits. (2) Members will be able to receive services at ASCs, and those providers will be able to receive reimbursement.

**FISCAL IMPACT OF THE RULE:** (1) Per the Public Law, providing a new methodology for calculating recapture of depreciation upon the sale of a nursing facility carries a potential current biennium cost increase, but the impact cannot be quantified at this time because it is dependent upon the timing and details of federal approval and on the timing and number of facility sales. (2) The Department estimates that the General Fund impact of adding reimbursement for Ventilator Care Services as a separately reimbursable service is \$220,792 in SFY 2016 and \$219,615 in SFY 2017.



10-144 Chapter 101  
MAINECARE BENEFITS MANUAL  
CHAPTER II

SECTION 67

NURSING FACILITY SERVICES ESTABLISHED 7/1/91  
LAST UPDATED 7/1/14

67.02 ELIGIBILITY FOR CARE (cont.)

- b. Impaired Self-Awareness
- c. Irritability, Anger, Aggression
- d. Inappropriate Social Interactions
- e. Fund of Information or Attention/Concentration or Memory

67.02-6 Medical Requirements for Members requiring Ventilator Care Services

A. Effective 7/1/15, if CMS approves, in order for a member to be medically eligible for Ventilator Care Services in a Nursing Facility the Member must be ventilator dependent and may be admitted from the following locations:

1. An Intensive Care Unit if the Member is no longer in need of ICU level of care; or
2. An Acute Care Facility if the Member is clinically stable; or
3. From their residence if they are receiving ventilator support in the home and the Member is no longer able to maintain a stable respiratory status.

B. Additionally, the Member must:

1. Have current documentation from a physician certifying the medical necessity of ventilator support;
2. Be unable to meet his/her respiratory needs via non-invasive ventilation (CPAP, BiPAP, etc.)

67.02-7 Extraordinary Circumstances (EC)

A. A nursing facility must request and receive written approval for a member's continued stay under "extraordinary circumstances." (Please refer to 67.05-4.). A NF MaineCare member whose length of stay has been reimbursed by MaineCare for more than one hundred-twenty (120) consecutive days may continue to stay in the NF due to "extraordinary circumstances" if it has been determined after documented discharge planning that:

1. There is no available, appropriate placement within a sixty (60) mile radius of the member's residence; AND
2. Discharge from the NF would pose serious risk to the individual's health, welfare, or safety.

The counting of one hundred-twenty (120) consecutive days may include short-term hospital stays (ten (10) or fewer days), but may not include any days accrued during an appeal process, which begins on the day the member requests an appeal with the Department (see Section 67.05-18).

B. MaineCare coverage for "extraordinary circumstances" shall be for a specified period approved by the Department. For coverage to continue beyond the approved period, the NF must submit a completed request form to the Department at least five (5) calendar days prior to the end date of the member's approved EC period. If appropriate, the Department will

10-144 Chapter 101  
MAINECARE BENEFITS MANUAL  
CHAPTER II

**SECTION 67**

**NURSING FACILITY SERVICES ESTABLISHED 7/1/91  
LAST UPDATED 7/1/14**

67.05 POLICIES AND PROCEDURES (cont.)

**I. Pharmaceutical Services**

All nursing facilities shall comply with State and Federal regulations that govern obtaining, dispensing and administering drugs and biologicals. Refer to the "Regulations Governing the Licensing and Functioning of Skilled Nursing Facilities and Nursing Facilities" for rules regarding pharmaceutical services.

A pharmacy affiliated through common ownership or control with a hospital and/or nursing facility is allowed to dispense covered MaineCare prescription drugs to MaineCare members in that facility. The drugs must be dispensed by a registered pharmacist, according to dispensing regulations. Drugs are to be billed in accordance with the Department's billing guidelines and drug claim processing system, at Average Wholesale Price (AWP) without professional fee. (Also see Section 80, Pharmacy Services.)

**J. Respiratory Therapy Services**

1. The following respiratory therapy services are included in the facility's per diem rate and shall not be billed separately:
  - a. Maintenance of artificial airways;
  - b. Therapeutic administration and monitoring of medical gases (especially oxygen), pharmacological active mists and aerosols;
  - c. Bronchial hygiene therapy, including deep breathing and coughing exercises, IPPB, postural drainage, chest percussion and vibration, and nasotracheal suctioning; and
  - d. periodic assessment and monitoring of acute and chronically ill members for indications for respiratory therapy services.
2. The following services shall not be provided by the direct care staff of the facility, but rather by the appropriate professional, unless effective 7/1/15, if CMS approves, the facility is eligible to receive the Ventilator Services rate as described in Chapter III, Section 67, Principle 42. Respiratory Therapy Services and shall be billed separately:
  - a. diagnostic tests for evaluation by a physician (e.g.: pulmonary function tests, spirometry, and blood gas analysis); and
  - b. pulmonary rehabilitation that includes exercise conditioning, breathing retraining, and patient education regarding the management of the member's respiratory problem.

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SECTION 67                      NURSING FACILITY SERVICES ESTABLISHED 7/1/91  
LAST UPDATED 7/1/14

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67.05    POLICIES AND PROCEDURES (cont.)

K.    Services for Members Requiring Ventilator Care

Effective 7/1/15, if CMS approves, the following services shall be provided by the appropriate professionals, and shall be billed separately: Ventilator Care for Members requiring 24 hour ventilator care or requiring weaning from a ventilator, under the care of a respiratory therapist and a pulmonologist. In order to provide this care, at a minimum, the facility must supply their own ventilators, employ or contract with a pulmonologist, have a Respiratory Therapist on staff 24 hours per day, employ a Respiratory Program Manager for a minimum of 20 hours per week, and have the staff required to meet the additional staffing needs of ventilator patients, equal to or more than 5.20 Transitional Care Unit staffing hours per Patient Day.

L.    Other Services

The attending physician's order is required for all other types of services provided in a NF (e.g.: psychological services, podiatric services, etc.). The individual providing the service shall bill in accordance with the policies and procedures in the section of this Manual that apply to his or her specialty.

67.05-14    **Transportation to Services Outside of the Nursing Facility**

A.    **Arranging or Providing Transportation**

NF's are required to assist members in gaining access to vision, hearing, or other medically necessary MaineCare services by making appointments, and providing or arranging for transportation. To enable a NF to provide transportation, the reasonable costs of operating one (1) motor vehicle is an allowable cost in the facility's reimbursement rate (as set forth in this Section, Chapter III, Principles of Reimbursement for Nursing Facilities). NF's must use their agency vehicle to transport members whenever possible. Each time a member is transported by someone other than a family member/friend, or the NF's agency vehicle, and for which MaineCare reimbursement will be sought, the member's record must document why the NF vehicle was not used.

B.    **Transportation Agency**

Effective August 1, 2013, when a member requires transportation to a MaineCare covered service, and the NF or a family member/friend is unable to provide it and the NF has documented why the transportation cannot be provided, then the MaineCare Non-Emergency Transportation (NET) Broker must be called to make travel arrangements. NF staffing shortages should not be an ongoing reason for NET services. It is the expectation that the NF is fully staffed and a need to use a transportation agency due to unavailable staff would not occur frequently.

42 **VENTILATOR CARE UNITS**

In order for a nursing facility to receive additional reimbursement for ventilator care, a nursing facility must meet all of the following criteria:

- The nursing facility must supply their own ventilators
- The nursing facility must employ or contract with a pulmonologist
- The nursing facility must have a Respiratory Therapist on staff 24 hours per day
- The nursing facility must employ a Respiratory Program Manager at least 20 hour per week
- The nursing facility must have the required additional staffing to meet the needs of ventilator dependent members, equal to or more than 5.20 staffing hours per patient day

**Principle.** A nursing facility with a qualifying ventilator care unit under this section will be reimbursed for the additional care associated with members receiving ventilator care according to the methodology outlined below.

**Rate setting.** Qualified providers must receive a prior authorization from the Department to bill for Ventilator Services. If approved, the provider will be reimbursed for ventilator care services as follows:

CPT code 94004 - \$322.36

This rate includes the following costs:

- a) Ventilator purchase or rental.
- b) Oxygen.
- c) Medical supplies.
- d) Respiratory manager salary and benefits.
- e) Respiratory therapist salary and benefits.
- f) Pulmonologist salary and benefits.
- g) Social worker salary and benefits.
- h) Activities aide salary and benefits, and
- i) All salary and benefit cost for any additional staff.

**Audit.** The additional ventilator care add-on will be considered an ancillary service. All costs including general & administrative costs associated with the provision of ventilator care services will be considered ancillary costs and will not be cost settled. Any capital costs that are incurred as a result of the development of the vent unit or due to the admission of a vent patient will also be considered ancillary costs that are not reimbursable during cost settlement and shall be considered included in the CPT code 94004 rate of \$322.36.

# MHA

## Maine Hospital Association

*Representing community hospitals and the patients they serve.*

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### Summary of the MHA's "Snapshot in Time" Days Awaiting Placement Survey for Inpatients

- 29/36 hospitals (80%) completed the Days Awaiting Placement Survey for inpatients
  - 27/29 (75%) had at least one patient awaiting appropriate placement
  - A total of 119 patients were waiting for the appropriate level of care
    - 43 patients had been waiting at least 40 days
    - 12 patients had been waiting 31-40 days
    - 13 patients had been waiting 21-30 days
    - 9 patients had been waiting 10-20 days
    - 42 patients had been waiting for 10 or fewer days
- 93% of respondents have experienced an increase in the number of days awaiting placement over the last 1-12 months.
  - 86% of respondents characterized the days awaiting placement as "It's difficult and getting worse over the last year."
- 52% of respondents said that this "snapshot in time" of days awaiting placement was typical for their hospital; 27% said it was heavier than usual; 21% said it was lighter than usual.

#### Level of care needed:

34 (29%) were waiting for a nursing home bed  
23 (19%) were waiting for a skilled nursing facility bed  
15 (13%) were waiting for an inpatient psychiatric bed  
14 (12%) were waiting for dementia care  
10 were waiting for residential care  
9 were waiting for psychiatric residential care  
4 were waiting for PNMI  
3 were waiting for an acute care bed  
2 were waiting for Crisis Stabilization Unit  
2 were waiting for outpatient psychiatric services  
1 was waiting for geropsych; 1 was waiting for ICF/MR; 1 was waiting for hospice

#### Most commonly cited barriers to appropriate placement:

Simply no bed available at the appropriate level of care: 31 (26%)  
Special needs: 24 patients (e.g. dialysis, ventilator dependency, bariatric, IV etc.) (20%)  
Facility of origin refused: 9 patients (7.6%)  
Behavioral issues: 9 patients  
MaineCare application process delays: 9 patients  
Other financial issues: 9 patients  
Guardianship process delays: 7 patients  
Unable to find a SNF bed because patient will need NF bed following rehab: 4

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# MHA

## Maine Hospital Association

Representing community hospitals and the patients they serve.

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### Focus on just those patients waiting $\geq 40$ days for the appropriate level of care...

43 patients (43/119 or 36%) were waiting for these levels of care:

- 16 nursing facility (37%)
- 8 dementia (19%)
- 6 psych res care (14%)
- 4 PNMI; 4 res care
- 2 inpatient psych; 2 skilled nursing facility
- 1 crisis stepdown unit

Barriers to appropriate placement for these 43 patients waiting  $\geq 40$  days:

39 no bed; 4 financial reasons

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### NOTES ON "BARRIERS TO PLACEMENT"

1. DDPC declined the patient despite having treated the patient previously
  2. On DDPC waiting list
  3. Special needs, chronic aggression and developmental delays
  4. Special needs, behavioral, facility of origin refused due to prior elopement, insists on private room
  5. Family renting her home, and not completing MaineCare paperwork
  6. Needs locked res care unit; known sex offender  
so none of the potential facilities in the state would accept
  7. Facility of origin refused; paraplegic in motorized wheelchair; drug addict; behavior issues;  
all facilities refusing
  8. Level of Care not specified but comments said: Has had 2 strokes and needs assistance
  9. Illegal alien; all facilities refused; Jamaican embassy of no help
  10. Violent person with MI
  11. Patient needs skilled intravenous therapy
  12. MaineCare pending
  13. MaineCare denied, spend-down requirements not met; legal counsel involved
  14. Currently SNF and appropriately in swing bed, but will need NF placement so couldn't find  
outside SNF bed
  15. Goolded in the community for NF & reassessed at hospital with same finding;  
needs bariatric equipment/private room
  16. Guardianship process delays
  17. Needs secured res care bed; guardianship process delays
  18. Dialysis, needs ambulance transfer; 7 skilled days left and MaineCare not approved
  19. Difficult family, refused to provide info for MaineCare application; APS now seeking guardianship
  20. Husband can't accept she can't come home & not providing info to determine if MaineCare needed
-

# MHA

## Maine Hospital Association

*Representing community hospitals and the patients they serve.*

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21. Medical needs include dialysis
  22. Needs Asst. Living Facility
  23. Awaiting MaineCare LTC approval
  24. HOSPITAL is waiting for an acute care bed at HOSPITAL
  25. Had to wait for MaineCare application, then Goold assessment
  26. Bariatric (>500 lbs); homeless
  27. Flight risk so requires locked dementia unit
  28. Patient is 9 years old and has been assessed by psychiatric professional
  29. Inadequate insurance; house condemned; significant debt; no financial POA; APS is involved
  30. No SNF will accept due to son's verbal/emotional abuse; completed SNF in hospital; refused assisted living; discharged home with APS & visiting nurse
  31. Local facilities refused to accept due to dysfunctional family relationships
  32. No MaineCare NF bed available within 60 miles of HOSPITAL and family refused bed in Portland
  - 33 Admitted from AL with COPD; multiple recent admissions. Awaiting MaineCare LTC application approval; Patient refused to return to assisted living facility and desires a NF bed in southern Maine to be closer to family
  34. Facility of origin (assisted living dementia unit) refused because he had 30 days out for medical admission over the last year; agitated dementia
  35. Admitted from home with terminal cancer; required placement of pleurex catheter which had to be ordered/inserted; facilities reluctant to accept due to catheter placement; just found private pay hospice that would accept the patient
  36. Admitted from home because husband could no longer care for her; difficulty with medication adjustments to balance agitated behavior versus EPS symptoms with somnolence
  37. Facility of origin refused; unspecified special need; unspecified financial issue
  38. Boarding homes refuse to take the patient due to advanced dementia with behavioral issues
  39. Found a bed, but they won't accept her without a payment source; patient given a notice of no coverage in the ED
  40. There have been some issues with her LTC application
  41. Denied at admission, not an acute level of care; lived alone; need to apply for MaineCare
  42. Non-documented alien; TBI with history of aggressive behavior; language barrier; HOSPITAL hired attorney to establish guardianship; no funding source for care; previously at NH funded by DHHS but funding ended and NH discharged him; lived in shelter until arriving in 2013
  43. Lived with daughter; agitated/violent behavior; needed to apply for MaineCare; needs dementia res care
  44. Patient has psych history with multiple discharges from various residential care facilities; was on PNMI wait list when brought to HOSPITAL; facility of origin refused
  45. Guardianship process delays; awaiting Goold assessment; TBI and problems establishing need for TBI bed and special TBI funding
  46. Needs residential program for developmental disabilities
  47. Facility of origin refused; patient needs high staff, intensive program
  48. Court committed for long hospitalization; transfer refused due to unspecified reason
-

# MHA

## Maine Hospital Association

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49. Facility of origin refused; unspecified special need
  50. Facility of origin refused; TBI
  51. Facility of origin recommended more staff intense facility
  52. Diagnosed with suicidal and homicidal ideation
  53. Diagnosed with OD-SI
  54. No facilities will accept due to complex medical and psych issues; non-compliant and has unsafe home environment; has applied for MaineCare
  55. Patient will require NF after SNF so no SNF facility will accept for fear of not being able to find NF bed when needed, leaving them "stuck without payment"
  56. We tried to give a letter of non-coverage, but the QIO overturned; so, very difficult to find placement
  57. MaineCare process started on admission, but not completed until a few days before she was discharged
  58. Worked with HOSPITAL to adjust meds so that the patient could go to NH instead of HOSPITAL, which had a wait list of up to 3 months. With family permission, admitted to NH in Orono
  59. Patient originally self-pay and unwilling to go to certain facilities. She finally completed spend-down while at HOSPITAL so then had to apply for MaineCare
  60. Discharge LOC need transitioned from SNF to NF while hospitalized
  61. Unspecified financial barrier
  62. Bariatric patient
  63. Huntington's patient
  64. Patient requires TPN and no facility has 24/7 RN to administer; cost of TPN
  65. Patient requires intravenous immunoglobulin (IVIG); family refusing to take patient home; insurance; delays to approve SNF
  66. IV drug user; no facility will accept; no payer; needs IV infusion and physician will not approve home plan with IV access
  67. Patient requires assistance of 3 people and hooyer lift; wife refused SNF and it took 3 days for her to accept that she could no longer care for the patient at home
  68. Patient refuses to participate; 59 years old; neuropsych evaluation pending
  69. Severe head injury; no rehab potential; needs 1:1 sitter 24/7
  70. Patient will need SNF to NF; no long term care payer; working with wife to complete MaineCare application since admission but she han't submitted it
  71. Patient needs suctioning so no SNF will accept
  72. Denied on admission as a "social admit"; chronic vent at night since 1999; no nursing facility will accept due to the vent
  73. Insurance coverage ended; took 6 days with DHHS to figure out that spend down was needed before eligible for MaineCare; discharged home on hospice under charity care
  74. Patient's significant other has "burned bridges with all SNFs"; patient on acute dialysis; refuses to file for MaineCare
  75. Has left multiple SNFs AMA; friends took her for a ride at last SNF and got into an accident; no SNF will accept
-



# Mentally Ill Languish In Hospital Emergency Rooms

APRIL 13, 2011 12:01 AM ET

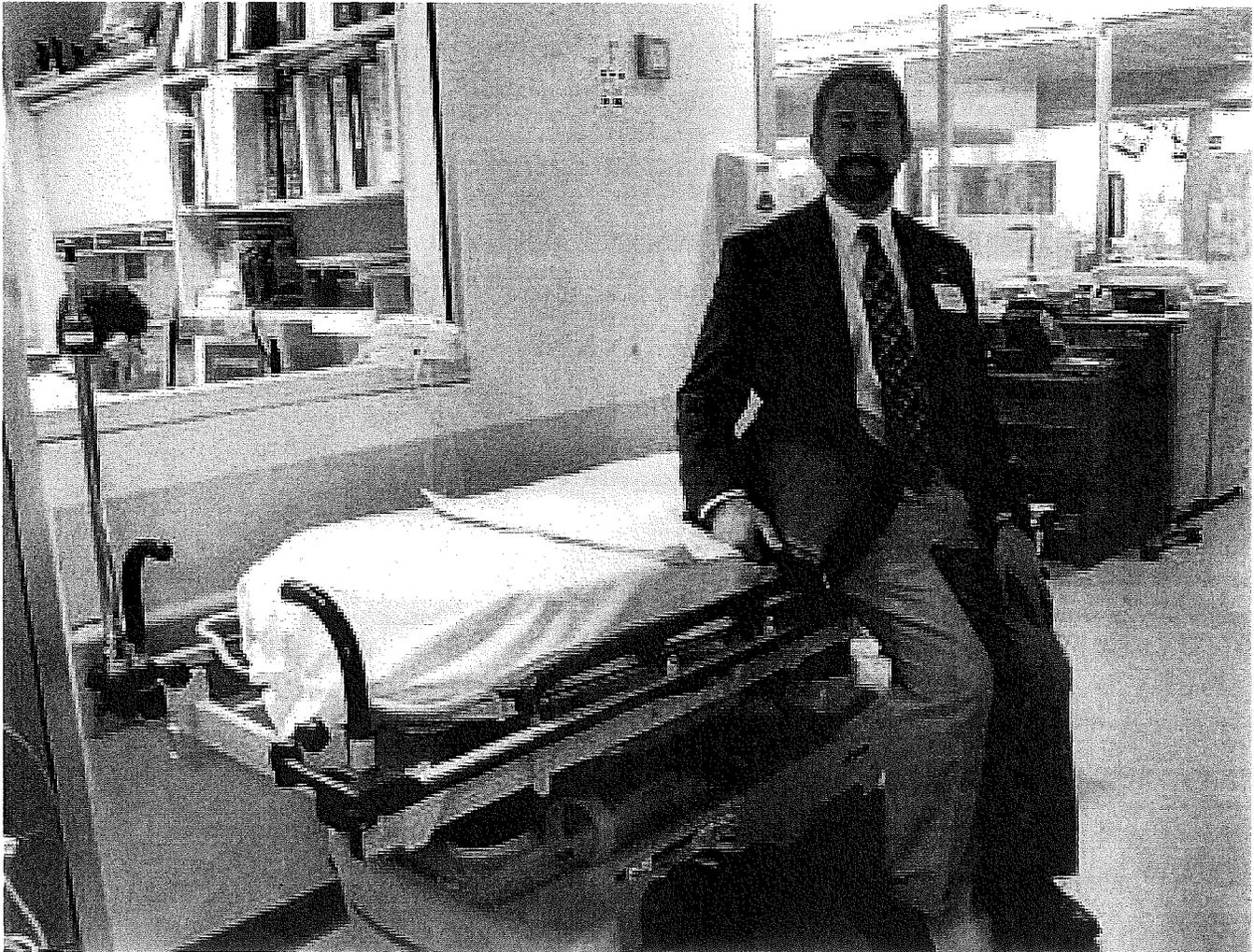
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"The inside of the ER is kind of like Las Vegas," with a "24/7, 365 flow of activity," says Dr. Gary Bubly, an emergency physician at The Miriam Hospital in Providence, R.I.

Jenny Gold for NPR

As he lay on a gurney in the emergency department of Memorial Hospital of Rhode Island, Erik grew increasingly upset. He had called the police to report a theft from his apartment, but wound up being taken to the hospital.

The ER staff quickly determined that Erik, 40, who has been diagnosed with schizoaffective disorder and PTSD, needed urgent psychiatric care, but there wasn't much they could do.

Like many hospitals, Memorial doesn't have a psychiatric unit, and all of the psychiatric units in the nearby facilities were full. Erik, a bright, articulate and devoutly religious man, had to wait nearly two days on a gurney in the ER before he could be transferred.

Mentally ill patients often languish in hospital emergency rooms for several days, sometimes longer, before they can be moved to a psychiatric unit or hospital. At most, they get drugs but little counseling, and the environment is often harsh.

"The inside of the ER is kind of like Las Vegas," with a "24/7, 365 flow of activity," says Dr. Gary Bubly, an emergency physician at the nearby Miriam Hospital and president of the Rhode Island Medical Society. While the ER staff does its best to care for mentally ill patients, he says, it's the wrong place for someone in the midst of a psychiatric crisis.

### **Budget Woes Cut Mental Health 'To The Bone'**

“

Emergency rooms are for people with heart attacks and gunshot wounds, and it is just a disgrace that mentally ill people can be held two, three, five days, eating ham sandwiches in total chaos.

H. Reed Cospser, Rhode Island's mental health advocate

Seventy percent of emergency department administrators report that they hold mentally ill patients for 24 hours or longer, according to a 2010 survey by the

Schumacher Group, a Louisiana firm that manages emergency departments across the country. Ten percent said they had boarded some patients for a week or more. Most administrators said delays compromise patient care in the ER, increasing waiting times for all patients and overcrowding.

The problem has worsened during the economic downturn. Since 2009, 32 states have cut their mental health budgets, largely from outpatient services that keep people healthy and out of the ER, according to a study by the National Alliance on Mental Illness, a patient advocacy group. And since 2010, states have closed or are planning to close nearly 4,000 state psychiatric beds, about 8 percent of capacity, according to the National Association of State Mental Health Program Directors Research Institute.

"We're not cutting fat anymore," says Charles Ingoglia, vice president of public policy at the National Council for Community Behavioral Healthcare, a membership organization for mental health organizations that treat the uninsured and underinsured. "We're at the bone. All of the easy cuts have already been made over the years."

At the same time, many Americans have lost their jobs and health insurance and are leaning on the state programs that are being cut. The need for such services has also grown as depression and anxiety have increased: A 2009 survey by the U.S. Substance Abuse and Mental Health Services Administration found that mental illness is more prevalent among unemployed adults. Many wait until their illness reaches a breaking point and then seek care at the ER.

### **'Like A Mute Prisoner With No Rights'**

Over the past few years, Erik says he has been stuck in the ER several times for anxiety and psychosis. He describes himself as a musician, and with his shoulder-length brown hair, mustache and goatee, he looks the part. He has health insurance through both Medicare and Medicaid and lives off of the monthly disability payments he receives from Social Security. He asked that his last name not be published for fear of being stigmatized.

When he arrived at Memorial, nurses asked Erik to remove his clothing and put on a hospital gown; he refused, saying it violated his religious beliefs. According to hospital

records, he threatened to punch a nurse who tried to get him to comply, and was bound by his wrists and ankles.

"I feel like a mute prisoner with no rights," he says of his experience in the emergency room. "It's pushing my tolerance and self-control thresholds to the maximum." A security guard sat by him, making sure he didn't try to hurt himself or leave the hospital. Even his visits to the bathroom were supervised.

Memorial Hospital wouldn't allow a reporter to visit the ER. But Miriam's emergency room regularly faces the same problem of psychiatric patients waiting a long time before they are transferred. The unit is divided into small patient quarters, each cordoned off with a pastel floral curtain that ends about two feet above the floor, providing no sound barrier for the chaos occurring just outside.

One recent Monday afternoon, more than 40 doctors and nurses were rushing back and forth with clipboards and stethoscopes, rolling patients on gurneys and tending to those parked in the narrow hallways. Phones were ringing off the hook, the loudspeaker was barking with pages for physicians, and medical monitors were beeping incessantly. There was no natural light — only the yellow glow of fluorescent lights overhead.

Two psychiatric patients were waiting for a bed. One had been there for 30 hours, the other for just a few. They were monitored day and night by a security guard sitting outside their curtained areas, slowing down the flow of traffic in the ER. For every hour that a mentally ill person is stuck there, another patient cannot get in. On this particular day, six people were waiting in the triage unit, and if not for the two psychiatric patients awaiting placement, Bubly says, they might otherwise have been seen already.

Bubly is frustrated with the situation, which he describes as "the thing that is most wrong with the health care system that I see on a daily basis." The long wait times for mentally ill patients would not be tolerated for any other illness, he says. "If somebody had pneumonia and they were admitted, they wouldn't be told they have to wait anywhere."



Craig Stenning, head of Rhode Island's mental health department, lets hospitals know where mental health patients are waiting and where beds might be available.

*Jenny Gold for NPR*

## Looking For Solutions

Unlike many other states, Rhode Island is actively trying to solve the growing problem. Between 2005 and 2009, psychiatric visits to the emergency department in the state increased by nearly 27 percent.

Since 2008, Craig Stenning, head of the state's mental health department, has been working with hospitals to communicate about where patients are waiting and where beds might be available. Each day around 2 p.m., his office puts out a list tracking mentally ill patients who are waiting for beds across the state. In the next six months, he hopes to begin an online program that allows hospitals to see the data in real time.

Stenning also added 49 beds in nonhospital settings to help ease the burden on

emergency rooms. Butler Hospital, the largest psychiatric hospital in the state, has received permission to add 26 beds in the next year.

Despite his efforts, some patients are still waiting a long time. H. Reed Coper, the state's mental health advocate, a lawyer appointed by the governor to defend and advance the rights of the mentally ill, recently received a complaint from a man whose 60-year-old mother waited for seven days before being transferred to a psychiatric hospital.

"Emergency rooms are for people with heart attacks and gunshot wounds, and it is just a disgrace that mentally ill people can be held two, three, five days, eating ham sandwiches in total chaos," he says.

Coper has been on the case for 20 years. While waiting times have gotten better, he says, letting patients languish in ERs is illegal in Rhode Island.

Emergency departments, Coper argues, fail to provide the basic rights guaranteed to psychiatric patients under Rhode Island's mental health law, including the right to privacy and dignity, to wear one's own clothes and to be given reasonable access to telephones to make and receive confidential calls.

### **Tranquility At The Psychiatric Hospital**

Forty-two hours after being brought by ambulance to Memorial Hospital, Erik was finally transferred to Butler Hospital. It's a sprawling brick building from the 19th century, with tall turrets and a glass gazebo out front, built on a 110-acre campus of conifers and deciduous trees looking out over the Seekonk River.

The hallways are a tranquil gray, and several paintings hang in the stairwells. Erik is wearing his own blue plaid flannel shirt and khakis, and his hair and mustache are carefully combed. At Butler, he explains, he feels safe and comfortable. He's allowed "to take a shower and use the facilities without someone watching me or insisting that the door be open. I think that's a minimal level of humanity that should be accorded to a human being."

Not all psychiatric hospitals are as picturesque as Butler, and many present their own share of problems. But at least they were designed for patients like Erik, who spent

seven days there before he was allowed to return home.

Today, he is scared that, before long, he'll end up stuck in an ER again.

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## THE HOT SPOTTERS

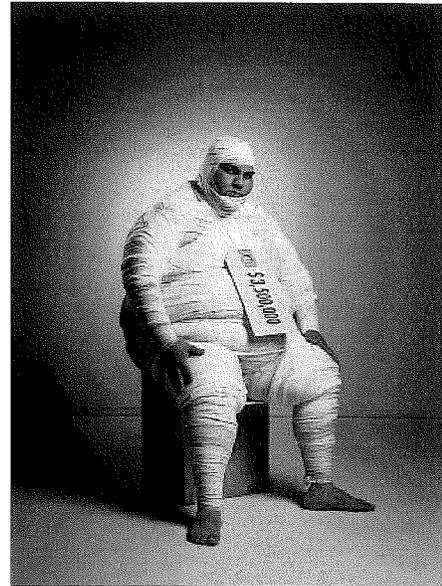
*Can we lower medical costs by giving the neediest patients better care?*

BY ATUL GAWANDE

*In Camden, New Jersey, one per cent of patients account for a third of the city's medical costs.*

PHOTOGRAPH BY PHILLIP TOLEDANO

If Camden, New Jersey, becomes the first American community to lower its medical costs, it will have a murder to thank. At nine-fifty on a February night in 2001, a twenty-two-year-old black man was shot while driving his Ford Taurus station wagon through a neighborhood on the edge of the Rutgers University campus. The victim lay motionless in the street beside the open door on the driver's side, as if the car had ejected him. A neighborhood couple, a physical therapist and a volunteer firefighter, approached to see if they could help, but police waved them back.



“He’s not going to make it,” an officer reportedly told the physical therapist. “He’s pretty much dead.” She called a physician, Jeffrey Brenner, who lived a few doors up the street, and he ran to the scene with a stethoscope and a pocket ventilation mask. After some discussion, the police let him enter the crime scene and attend to the victim. Witnesses told the local newspaper that he was the first person to lay hands on the man.

“He was slightly overweight, turned on his side,” Brenner recalls. There was glass everywhere. Although the victim had been shot several times and many minutes had passed, his body felt warm. Brenner checked his neck for a carotid pulse. The man was alive. Brenner began the chest compressions and rescue breathing that should have been started long before. But the young man, who turned out to be a Rutgers student, died soon afterward.

The incident became a local scandal. The student’s injuries may not have been survivable, but the police couldn’t have known that. After the ambulance came, Brenner confronted one of the officers to ask why they hadn’t tried to rescue him.

“We didn’t want to dislodge the bullet,” he recalls the policeman saying. It was a ridiculous answer, a brushoff, and Brenner couldn’t let it go.

He was thirty-one years old at the time, a skinny, thick-bearded, soft-spoken family physician who had grown up in a bedroom suburb of Philadelphia. As a medical student at Robert Wood Johnson Medical School, in Piscataway, he had planned to become a neuroscientist. But he volunteered once a week in a free primary-care clinic for poor immigrants, and he found the work there more challenging than anything he was doing in the laboratory. The guy studying neuronal stem cells soon became the guy studying Spanish and training to become one of the few family physicians in his class. Once he completed his residency, in 1998, he joined the staff of a family-medicine practice in Camden. It was in a cheaply constructed, boxlike, one-story building on a desolate street of bars, car-repair shops, and empty lots. But he was young and eager to recapture the sense of purpose he’d felt volunteering at the clinic during medical school.

Few people shared his sense of possibility. Camden was in civic free fall, on its way to becoming one of the poorest, most crime-ridden cities in the nation. The local school system had gone into receivership. Corruption and mismanagement soon prompted a state takeover of the entire city. Just getting the sewage system to work could be a problem. The neglect of this anonymous shooting victim on Brenner’s street was another instance of a city that had given up, and Brenner was tired of wondering why it had to be that way.

Around that time, a police reform commission was created, and Brenner was asked to serve as one of its two citizen members. He agreed and, to his surprise, became completely absorbed. The experts they called in explained the basic principles of effective community policing. He learned about George Kelling and James Q. Wilson’s “broken-windows” theory, which argued that minor, visible neighborhood disorder breeds major crime. He learned about the former New York City police commissioner William Bratton and the Compstat approach to policing that he had championed in the nineties, which centered on mapping crime and focussing resources on the hot spots. The reform panel pushed the Camden Police Department to create computerized crime maps, and to change police beats and shifts to focus on the worst areas and times.

When the police wouldn’t make the crime maps, Brenner made his own. He persuaded Camden’s three main hospitals to let him have access to their medical billing records. He transferred the reams of data files onto a desktop computer, spent weeks figuring out how to pull the chaos of information into a searchable database, and then started tabulating the emergency-room visits of victims of serious assault. He created maps showing where the crime victims lived. He pushed for policies that would let the Camden police chief assign shifts based on the crime statistics—only to find himself in a showdown with the police unions.

“He has no clue,” the president of the city police superiors’ union said to the *Philadelphia Inquirer*. “I just think that his comments about what kind of schedule we should be on, how we should be deployed, are laughable.”

The unions kept the provisions out of the contract. The reform commission disbanded; Brenner withdrew from the cause, beaten. But he continued to dig into the database on his computer, now mostly out of idle interest.

Besides looking at assault patterns, he began studying patterns in the way patients flowed into and out of Camden’s hospitals. “I’d just sit there and play with the data for hours,” he says, and the more he played the more he found. For instance, he ran the data on the locations where ambulances picked up patients with fall injuries, and discovered that a single building in central Camden sent more people to the hospital with serious falls—fifty-seven elderly in two years—than any other in the city, resulting in almost three million dollars in health-care bills. “It was just this amazing window into the health-care delivery system,” he says.

So he took what he learned from police reform and tried a Compstat approach to the city’s health-care performance—a Healthstat, so to speak. He made block-by-block maps of the city, color-coded by the hospital costs of its residents, and looked for the hot spots. The two most expensive city blocks were in north Camden, one that had a large nursing home called Abigail House and one that had a low-income housing tower called Northgate II. He found that between January of 2002 and June of 2008 some nine hundred people in the two buildings accounted for more than four thousand hospital visits and about two hundred million dollars in health-care bills. One patient had three hundred and twenty-four admissions in five years. The most expensive patient cost insurers \$3.5 million.

Brenner wasn’t all that interested in costs; he was more interested in helping people who received bad health care. But in his experience the people with the highest medical costs—the people cycling in and out of the hospital—were usually the people receiving the worst care. “Emergency-room visits and hospital admissions should be considered failures of the health-care system until proven otherwise,” he told me—failures of prevention and of timely, effective care.

If he could find the people whose use of medical care was highest, he figured, he could do something to help them. If he helped them, he would also be lowering their health-care costs. And, if the stats approach to crime was right, targeting those with the highest health-care costs would help lower the entire city’s health-care costs. His calculations revealed that just one per cent of the hundred thousand people who made use of Camden’s medical facilities accounted for thirty per cent of its costs. That’s only a thousand people—about half the size of a typical family physician’s panel of patients.

Things, of course, got complicated. It would have taken months to get the approvals needed to pull names out of the data and approach people, and he was impatient to get started. So, in the spring of 2007, he held a meeting with a few social workers and emergency-room doctors from hospitals around the city. He showed them the cost statistics and use patterns of the most expensive one per cent. “These are the people I want to help you with,” he said. He asked for assistance reaching them. “Introduce me to your worst-of-the-worst patients,” he said.

They did. Then he got permission to look up the patients’ data to confirm where they were on his cost map. “For all the stupid, expensive, predictive-modelling software that the big venders sell,” he says, “you just ask the doctors, ‘Who are your most difficult patients?’, and they can identify them.”

*“Can you imagine how being the only one here makes me feel?”*

The first person they found for him was a man in his mid-forties whom I’ll call Frank Hendricks.

Hendricks had severe congestive heart failure, chronic asthma, uncontrolled diabetes, hypothyroidism, gout, and a history of smoking and alcohol abuse. He weighed five hundred and sixty pounds. In the previous three years, he had spent as much time in hospitals as out. When Brenner met him, he was in intensive care with a tracheotomy and a feeding tube, having developed septic shock from a gallbladder infection.



Brenner visited him daily. “I just basically sat in his room like I was a third-year med student, hanging out with him for an hour, hour and a half every day, trying to figure out what makes the guy tick,” he recalled. He learned that Hendricks used to be an auto detailer and a cook. He had a longtime girlfriend and two children, now grown. A toxic combination of poor health, Johnnie Walker Red, and, it emerged, cocaine addiction had left him unreliably employed, uninsured, and living in a welfare motel. He had no consistent set of doctors, and almost no prospects for turning his situation around.

After several months, he had recovered enough to be discharged. But, out in the world, his life was simply another hospitalization waiting to happen. By then, however, Brenner had figured out a few things he could do to help. Some of it was simple doctor stuff. He made sure he followed Hendricks closely enough to recognize when serious problems were emerging. He double-checked that the plans and prescriptions the specialists had made for Hendricks’s many problems actually fit together—and, when they didn’t, he got

on the phone to sort things out. He teamed up with a nurse practitioner who could make home visits to check blood-sugar levels and blood pressure, teach Hendricks about what he could do to stay healthy, and make sure he was getting his medications.

A lot of what Brenner had to do, though, went beyond the usual doctor stuff. Brenner got a social worker to help Hendricks apply for disability insurance, so that he could leave the chaos of welfare motels, and have access to a consistent set of physicians. The team also pushed him to find sources of stability and value in his life. They got him to return to Alcoholics Anonymous, and, when Brenner found out that he was a devout Christian, he urged him to return to church. He told Hendricks that he needed to cook his own food once in a while, so he could get back in the habit of doing it. The main thing he was up against was Hendricks's hopelessness. He'd given up. "Can you imagine being in the hospital that long, what that does to you?" Brenner asked.

I spoke to Hendricks recently. He has gone without alcohol for a year, cocaine for two years, and smoking for three years. He lives with his girlfriend in a safer neighborhood, goes to church, and weathers family crises. He cooks his own meals now. His diabetes and congestive heart failure are under much better control. He's lost two hundred and twenty pounds, which means, among other things, that if he falls he can pick himself up, rather than having to call for an ambulance.

"The fun thing about this work is that you can be there when the light switch goes on for a patient," Brenner told me. "It doesn't happen at the pace we want. But you can see it happen."

With Hendricks, there was no miraculous turnaround. "Working with him didn't feel any different from working with any patient on smoking, bad diet, not exercising—working on any particular rut someone has gotten into," Brenner said. "People are people, and they get into situations they don't necessarily plan on. My philosophy about primary care is that the only person who has changed anyone's life is their mother. The reason is that she cares about them, and she says the same simple thing over and over and over." So he tries to care, and to say a few simple things over and over and over.

I asked Hendricks what he made of Brenner when they first met.

"He struck me as odd," Hendricks said. "His appearance was not what I expected of a young, clean-cut doctor." There was that beard. There was his manner, too. "His whole premise was 'I'm here for you. I'm not here to be a part of the medical system. I'm here to get you back on your feet.'"

An ordinary cold can still be a major setback for Hendricks. He told me that he'd been in the hospital four times this past summer. But the stays were a few days at most, and he's had no more cataclysmic, weeks-long I.C.U. stays.

Was this kind of success replicable? As word went out about Brenner's interest in patients like Hendricks, he received more referrals. Camden doctors were delighted to have someone help with their "worst of the worst." He took on half a dozen patients, then two dozen, then more. It became increasingly difficult to do this work alongside his regular medical practice. The clinic was already under financial strain, and received nothing for assisting these patients. If it were up to him, he'd recruit a whole staff of primary-care doctors and nurses and social workers, based right in the neighborhoods where the costliest patients lived. With the tens of millions of dollars in hospital bills they could save, he'd pay the staff double to serve as Camden's elite medical force and to rescue the city's health-care system.

But that's not how the health-insurance system is built. So he applied for small grants from philanthropies like the Robert Wood Johnson Foundation and the Merck Foundation. The money allowed him to ramp up his data system and hire a few people, like the nurse practitioner and the social worker who had helped him with Hendricks. He had some desk space at Cooper Hospital, and he turned it over to what he named the Camden Coalition of Healthcare Providers. He spoke to people who had been doing similar work, studied "medical home" programs for the chronically ill in Seattle, San Francisco, and Pennsylvania, and adopted some of their lessons. By late 2010, his team had provided care for more than three hundred people on his "super-utilizer" map.

I spent a day with Kathy Jackson, the nurse practitioner, and Jessica Cordero, a medical assistant, to see what they did. The Camden Coalition doesn't have enough money for a clinic where they can see patients. They rely exclusively on home visits and phone calls.

Over the phone, they inquire about emerging health issues, check for insurance or housing problems, ask about unfilled prescriptions. All the patients get the team's urgent-call number, which is covered by someone who can help them through a health crisis. Usually, the issue can be resolved on the spot—it's a headache or a cough or the like—but sometimes it requires an unplanned home visit, to perform an examination, order some tests, provide a prescription. Only occasionally does it require an emergency room.

Patients wouldn't make the call in the first place if the person picking up weren't someone like Jackson or Brenner—someone they already knew and trusted. Even so, patients can disappear for days or weeks at a time. "High-utilizer work is about building relationships with people who are in crisis," Brenner said. "The ones you build a relationship with, you can change behavior. Half we can build a relationship with. Half we can't."

One patient I spent time with illustrated the challenges. If you were a doctor meeting him in your office, you would quickly figure out that his major problems were moderate developmental deficits and out-of-control hypertension and diabetes. His blood pressure

and blood sugars were so high that, at the age of thirty-nine, he was already developing blindness and advanced kidney disease. Unless something changed, he was perhaps six months away from complete kidney failure.

You might decide to increase his insulin dose and change his blood-pressure medicine. But you wouldn't grasp what the real problem was until you walked up the cracked concrete steps of the two-story brownstone where he lives with his mother, waited for him to shove aside the old newspapers and unopened mail blocking the door, noticed Cordero's shake of the head warning you not to take the rumpled seat he's offering because of the ant trail running across it, and took in the stack of dead computer monitors, the barking mutt chained to an inner doorway, and the rotten fruit on a newspaper-covered tabletop. According to a state evaluation, he was capable of handling his medications, and, besides, he lived with his mother, who could help. But one look made it clear that they were both incapable.

*"Harry seldom leaves his retirement cubicle."*

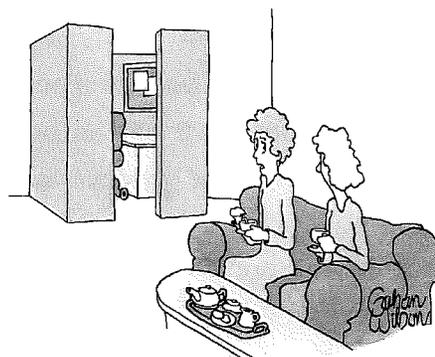
Jackson asked him whether he was taking his blood-pressure pills each day. Yes, he said. Could he show her the pill bottles? As it turned out, he hadn't taken any pills since she'd last visited, the week before. His finger-stick blood sugar was twice the normal level.

He needed a better living situation. The state had turned him down for placement in supervised housing, pointing to his test scores. But after months of paperwork—during which he steadily worsened, passing in and out of hospitals—the team was finally able to get him into housing where his medications could be dispensed on a schedule. He had made an overnight visit the previous weekend to test the place out.

"I liked it," he said. He moved in the next week. And, with that, he got a chance to avert dialysis—and its tens of thousands of dollars in annual costs—at least for a while.

Not everyone lets the team members into his or her life. One of their patients is a young woman of no fixed address, with asthma and a crack-cocaine habit. The crack causes severe asthma attacks and puts her in the hospital over and over again. The team members have managed occasionally to track her down in emergency rooms or recognize her on street corners. All they can do is give her their number, and offer their help if she ever wanted it. She hasn't.

Work like this has proved all-consuming. In May, 2009, Brenner closed his regular medical practice to focus on the program full time. It remains unclear how the program will make ends meet. But he and his team appear to be having a major impact. The



Camden Coalition has been able to measure its long-term effect on its first thirty-six super-utilizers. They averaged sixty-two hospital and E.R. visits per month before joining the program and thirty-seven visits after—a forty-per-cent reduction. Their hospital bills averaged \$1.2 million per month before and just over half a million after—a fifty-six-per-cent reduction.

These results don't take into account Brenner's personnel costs, or the costs of the medications the patients are now taking as prescribed, or the fact that some of the patients might have improved on their own (or died, reducing their costs permanently). The net savings are undoubtedly lower, but they remain, almost certainly, revolutionary. Brenner and his team are out there on the boulevards of Camden demonstrating the possibilities of a strange new approach to health care: to look for the most expensive patients in the system and then direct resources and brainpower toward helping them.

**J**eff Brenner has not been the only one to recognize the possibilities in focussing on the hot spots of medicine. One Friday afternoon, I drove to an industrial park on the outskirts of Boston, where a rapidly growing data-analysis company called Verisk Health occupies a floor of a nondescript office complex. It supplies "medical intelligence" to organizations that pay for health benefits—self-insured businesses, many public employers, even the government of Abu Dhabi.

Privacy laws prevent U.S. employers from looking at the details of their employees' medical spending. So they hand their health-care payment data over to companies that analyze the patterns and tell them how to reduce their health-insurance spending. Mostly, these companies give financial advice on changing benefits—telling them, say, to increase employee co-payments for brand-name drugs or emergency-room visits. But even employers who cut benefits find that their costs continue to outpace their earnings. Verisk, whose clients pay health-care bills for fifteen million patients, is among the data companies that are trying a more sophisticated approach.

Besides the usual statisticians and economists, Verisk recruited doctors to dive into the data. I met one of them, Nathan Gunn, who was thirty-six years old, had completed his medical training at the University of California, San Francisco, and was practicing as an internist part time. The rest of his time he worked as Verisk's head of research. Mostly, he was in meetings or at his desk poring through "data runs" from clients. He insisted that it was every bit as absorbing as seeing sick patients—sometimes more so. Every data run tells a different human story, he said.

At his computer, he pulled up a data set for me, scrubbed of identifying information, from a client that manages health-care benefits for some two hundred and fifty employers—school districts, a large church association, a bus company, and the like. They had a hundred thousand "covered lives" in all. Payouts for those people rose eight per cent a year, at least three times as fast as the employers' earnings. This wasn't good, but the

numbers seemed pretty dry and abstract so far. Then he narrowed the list to the top five per cent of spenders—just five thousand people accounted for almost sixty per cent of the spending—and he began parsing further.

“Take two ten-year-old boys with asthma,” he said. “From a disease standpoint, they’re exactly the same cost, right? Wrong. Imagine one of those kids never fills his inhalers and has been in urgent care with asthma attacks three times over the last year, probably because Mom and Dad aren’t really on top of it.” That’s the sort of patient Gunn uses his company’s medical-intelligence software program to zero in on—a patient who is sick and getting inadequate care. “That’s really the sweet spot for preventive care,” Gunn said.

He pulled up patients with known coronary-artery disease. There were nine hundred and twenty-one, he said, reading off the screen. He clicked a few more times and raised his eyebrows. One in seven of them had not had a full office visit with a physician in more than a year. “You can do something about that,” he said.

“Let’s do the E.R.-visit game,” he went on. “This is a fun one.” He sorted the patients by number of visits, much as Jeff Brenner had done for Camden. In this employed population, the No. 1 patient was a twenty-five-year-old woman. In the past ten months, she’d had twenty-nine E.R. visits, fifty-one doctor’s office visits, and a hospital admission.

“I can actually drill into these claims,” he said, squinting at the screen. “All these claims here are migraine, migraine, migraine, migraine, headache, headache, headache.” For a twenty-five-year-old with her profile, he said, medical payments for the previous ten months would be expected to total twenty-eight hundred dollars. Her actual payments came to more than fifty-two thousand dollars—for “headaches.”

Was she a drug seeker? He pulled up her prescription profile, looking for narcotic prescriptions. Instead, he found prescriptions for insulin (she was apparently diabetic) and imipramine, an anti-migraine treatment. Gunn was struck by how faithfully she filled her prescriptions. She hadn’t missed a single renewal—“which is actually interesting,” he said. That’s not what you usually find at the extreme of the cost curve.

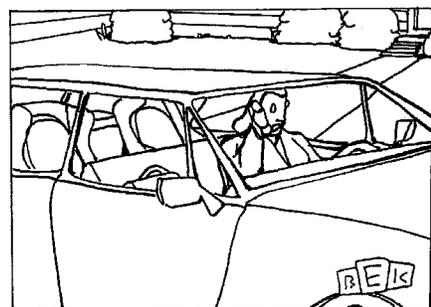
The story now became clear to him. She suffered from terrible migraines. She took her medicine, but it wasn’t working. When the headaches got bad, she’d go to the emergency room or to urgent care. The doctors would do CT and MRI scans, satisfy themselves that she didn’t have a brain tumor or an aneurysm, give her a narcotic injection to stop the headache temporarily, maybe renew her imipramine prescription, and send her home, only to have her return a couple of weeks later and see whoever the next doctor on duty was. She wasn’t getting what she needed for adequate migraine care—a primary physician taking her in hand, trying different medications in a systematic way, and figuring out how to better keep her headaches at bay.

As he sorts through such stories, Gunn usually finds larger patterns, too. He told me about an analysis he had recently done for a big information-technology company on the East Coast. It provided health benefits to seven thousand employees and family members, and had forty million dollars in “spend.” The firm had already raised the employees’ insurance co-payments considerably, hoping to give employees a reason to think twice about unnecessary medical visits, tests, and procedures—make them have some “skin in the game,” as they say. Indeed, almost every category of costly medical care went down: doctor visits, emergency-room and hospital visits, drug prescriptions. Yet employee health costs continued to rise—climbing almost ten per cent each year. The company was baffled.

Gunn’s team took a look at the hot spots. The outliers, it turned out, were predominantly early retirees. Most had multiple chronic conditions—in particular, coronary-artery disease, asthma, and complex mental illness. One had badly worsening heart disease and diabetes, and medical bills over two years in excess of eighty thousand dollars. The man, dealing with higher co-payments on a fixed income, had cut back to filling only half his medication prescriptions for his high cholesterol and diabetes. He made few doctor visits. He avoided the E.R.—until a heart attack necessitated emergency surgery and left him disabled with chronic heart failure.

The higher co-payments had backfired, Gunn said. While medical costs for most employees flattened out, those for early retirees jumped seventeen per cent. The sickest patients became much more expensive because they put off care and prevention until it was too late.

*“I thought that driving around all day picking kids up and dropping them off, then waiting for them, would be more fulfilling.”*



The critical flaw in our health-care system that people like Gunn and Brenner are finding is that it was never designed for the kind of patients who incur the highest costs. Medicine’s primary mechanism of service is the doctor visit and the E.R.

visit. (Americans make more than a billion such visits each year, according to the Centers for Disease Control.) For a thirty-year-old with a fever, a twenty-minute visit to the doctor’s office may be just the thing. For a pedestrian hit by a minivan, there’s nowhere better than an emergency room. But these institutions are vastly inadequate for people with complex problems: the forty-year-old with drug and alcohol addiction; the eighty-four-year-old with advanced Alzheimer’s disease and a pneumonia; the sixty-year-old

with heart failure, obesity, gout, a bad memory for his eleven medications, and half a dozen specialists recommending different tests and procedures. It's like arriving at a major construction project with nothing but a screwdriver and a crane.

Outsiders tend to be the first to recognize the inadequacies of our social institutions. But, precisely because they are outsiders, they are usually in a poor position to fix them. Gunn, though a doctor, mostly works for people who do not run health systems—employers and insurers. So he counsels them about ways to tinker with the existing system. He tells them how to change co-payments and deductibles so they at least aren't making their cost problems worse. He identifies doctors and hospitals that seem to be providing particularly ineffective care for high-needs patients, and encourages clients to shift contracts. And he often suggests that clients hire case-management companies—a fast-growing industry with telephone banks of nurses offering high-cost patients advice in the hope of making up for the deficiencies of the system.

The strategy works, sort of. Verisk reports that most of its clients can slow the rate at which their health costs rise, at least to some extent. But few have seen decreases, and it's not obvious that the improvements can be sustained. Brenner, by contrast, is reinventing medicine from the inside. But he does not run a health-care system, and had to give up his practice to sustain his work. He is an outsider on the inside. So you might wonder whether medical hot-spotting can really succeed on a scale that would help large populations. Yet there are signs that it can.

A recent Medicare demonstration program, given substantial additional resources under the new health-care-reform law, offers medical institutions an extra monthly payment to finance the coordination of care for their most chronically expensive beneficiaries. If total costs fall more than five per cent compared with those of a matched set of control patients, the program allows institutions to keep part of the savings. If costs fail to decline, the institutions have to return the monthly payments.

Several hospitals took the deal when the program was offered, in 2006. One was the Massachusetts General Hospital, in Boston. It asked a general internist named Tim Ferris to design the effort. The hospital had twenty-six hundred chronically high-cost patients, who together accounted for sixty million dollars in annual Medicare spending. They were in nineteen primary-care practices, and Ferris and his team made sure that each had a nurse whose sole job was to improve the coordination of care for these patients. The doctors saw the patients as usual. In between, the nurses saw them for longer visits, made surveillance phone calls, and, in consultation with the doctors, tried to recognize and address problems before they resulted in a hospital visit.

Three years later, hospital stays and trips to the emergency room have dropped more than fifteen per cent. The hospital hit its five-per-cent cost-reduction target. And the team is just getting the hang of what it can do.

**R**ecently, I visited an even more radically redesigned physician practice, in Atlantic City. Cross the bridge into town (Atlantic City is on an island, I learned), ignore the Trump Plaza and Caesars casinos looming ahead of you, drive a few blocks along the Monopoly-board streets (the game took its street names from here), turn onto Tennessee Avenue, and enter the doctors' office building that's across the street from the ninety-nine-cent store and the city's long-shuttered supermarket. On the second floor, just past the occupational-health clinic, you will find the Special Care Center. The reception area, with its rustic taupe upholstery and tasteful lighting, looks like any other doctors' office. But it houses an experiment started in 2007 by the health-benefit programs of the casino workers' union and of a hospital, AtlantiCare Medical Center, the city's two largest pools of employees.

Both are self-insured—they are large enough to pay for their workers' health care directly—and both have been hammered by the exploding costs. Yes, even hospitals are having a hard time paying their employees' medical bills. As for the union, its contracts are frequently for workers' total compensation—wages plus benefits. It gets a fixed pot. Year after year, the low-wage busboys, hotel cleaners, and kitchen staff voted against sacrificing their health benefits. As a result, they have gone without a wage increase for years. Out of desperation, the union's health fund and the hospital decided to try something new. They got a young Harvard internist named Rushika Fernandopulle to run a clinic exclusively for workers with exceptionally high medical expenses.

Fernandopulle, who was born in Sri Lanka and raised in Baltimore, doesn't seem like a radical when you meet him. He's short and round-faced, smiles a lot, and displays two cute rabbit teeth as he tells you how ridiculous the health-care system is and how he plans to change it all. Jeff Brenner was on his advisory board, along with others who have pioneered the concept of intensive outpatient care for complex high-needs patients. The hospital provided the floor space. Fernandopulle created a point system to identify employees likely to have high recurrent costs, and they were offered the chance to join the new clinic.

The Special Care Center reinvented the idea of a primary-care clinic in almost every way. The union's and the hospital's health funds agreed to switch from paying the doctors for every individual office visit and treatment to paying a flat monthly fee for each patient. That cut the huge expense that most clinics incur from billing paperwork. The patients were given unlimited access to the clinic without charges—no co-payments, no insurance bills. This, Fernandopulle explained, would force doctors on staff to focus on service, in order to retain their patients and the fees they would bring.

The payment scheme also allowed him to design the clinic around the things that sick, expensive patients most need and value, rather than the ones that pay the best. He adopted an open-access scheduling system to guarantee same-day appointments for the acutely ill. He customized an electronic information system that tracks whether patients

are meeting their goals. And he staffed the clinic with people who would help them do it. One nurse practitioner, for instance, was responsible for trying to get every smoker to quit.

I got a glimpse of how unusual the clinic is when I sat in on the staff meeting it holds each morning to review the medical issues of the patients on the appointment books. There was, for starters, the very existence of the meeting. I had never seen this kind of daily huddle at a doctor's office, with clinicians popping open their laptops and pulling up their patient lists together. Then there was the particular mixture of people who squeezed around the conference table. As in many primary-care offices, the staff had two physicians and two nurse practitioners. But a full-time social worker and the front-desk receptionist joined in for the patient review, too. And, outnumbering them all, there were eight full-time "health coaches."

Fernandopulle created the position. Each health coach works with patients—in person, by phone, by e-mail—to help them manage their health. Fernandopulle got the idea from the *promotoras*, community health workers, whom he had seen on a medical mission in the Dominican Republic. The coaches work with the doctors but see their patients far more frequently than the doctors do, at least once every two weeks. Their most important attribute, Fernandopulle explained, is a knack for connecting with sick people, and understanding their difficulties. Most of the coaches come from their patients' communities and speak their languages. Many have experience with chronic illness in their own families. (One was himself a patient in the clinic.) Few had clinical experience. I asked each of the coaches what he or she had done before working in the Special Care Center. One worked the register at a Dunkin' Donuts. Another was a Sears retail manager. A third was an administrative assistant at a casino.

"We recruit for attitude and train for skill," Fernandopulle said. "We don't recruit from health care. This kind of care requires a very different mind-set from usual care. For example, what is the answer for a patient who walks up to the front desk with a question? The answer is 'Yes.' 'Can I see a doctor?' 'Yes.' 'Can I get help making my ultrasound appointment?' 'Yes.' Health care trains people to say no to patients." He told me that he'd had to replace half of the clinic's initial hires—including a doctor—because they didn't grasp the focus on patient service.

In forty-five minutes, the staff did a rapid run-through of everyone's patients. They reviewed the requests that patients had made by e-mail or telephone, the plans for the ones who had appointments that day. Staff members made sure that all patients who made a sick visit the day before got a follow-up call within twenty-four hours, that every test ordered was reviewed, that every unexpected problem was addressed.

*"I've decided to leave my family to devote more time to myself."*

Most patients required no more than a ten-second mention. Mr. Green didn't turn up for his cardiac testing or return calls about it. "I know where his wife works. I'll track her down," the receptionist said. Ms. Blue is pregnant and on a high-blood-pressure medication that's unsafe in pregnancy. "I'll change her prescription right now," her doctor said, and keyed it in. A handful of patients required longer discussion. One forty-five-year-old heart-disease patient had just had blood tests that showed worsening kidney failure. The team decided to repeat the blood tests that morning, organize a kidney ultrasound in the afternoon if the tests confirmed the finding, and have him seen in the office at the end of the day.



A staff member read out the hospital census. Of the clinic's twelve hundred chronically ill patients, just one was in the hospital, and she was being discharged. The clinic's patients had gone four days without a single E.R. visit. On hearing this news, staffers cheered and broke into applause.

Afterward, I met a patient, Vibha Gandhi. She was fifty-seven years old and had joined the clinic after suffering a third heart attack. She and her husband, Bharat, are Indian immigrants. He cleans casino bathrooms for thirteen dollars an hour on the night shift. Vibha has long had poor health, with diabetes, obesity, and congestive heart failure, but things got much worse in the summer of 2009. A heart attack landed her in intensive care, and her coronary-artery disease proved so advanced as to be inoperable. She arrived in a wheelchair for her first clinic visit. She could not walk more than a few steps without losing her breath and getting a viselike chest pain. The next step for such patients is often a heart transplant.

A year and a half later, she is out of her wheelchair. She attends the clinic's Tuesday yoga classes. With the help of a walker, she can go a quarter mile without stopping. Although her condition is still fragile—she takes a purseful of medications, and a bout of the flu would send her back to an intensive-care unit—her daily life is far better than she once imagined.

"I didn't think I would live this long," Vibha said through Bharat, who translated her Gujarati for me. "I didn't want to live."

I asked her what had made her better. The couple credited exercise, dietary changes, medication adjustments, and strict monitoring of her diabetes.

But surely she had been encouraged to do these things after her first two heart attacks. What made the difference this time?

“Jayshree,” Vibha said, naming the health coach from Dunkin’ Donuts, who also speaks Gujarati.

“Jayshree pushes her, and she listens to her only and not to me,” Bharat said.

“Why do you listen to Jayshree?” I asked Vibha.

“Because she talks like my mother,” she said.

**F**ernandopulle carefully tracks the statistics of those twelve hundred patients. After twelve months in the program, he found, their emergency-room visits and hospital admissions were reduced by more than forty per cent. Surgical procedures were down by a quarter. The patients were also markedly healthier. Among five hundred and three patients with high blood pressure, only two were in poor control. Patients with high cholesterol had, on average, a fifty-point drop in their levels. A stunning sixty-three per cent of smokers with heart and lung disease quit smoking. In surveys, service and quality ratings were high.

But was the program saving money? The team, after all, was more expensive than typical primary care. And certain costs shot up. Because patients took their medications more consistently, drug costs were higher. The doctors ordered more mammograms and diagnostic tests, and caught and treated more cancers and other conditions. There’s also the statistical phenomenon known as “regression to the mean”: the super-high-cost patients may have been on their way to getting better (and less costly) on their own.

So the union’s health fund enlisted an independent economist to evaluate the clinic’s one-year results. According to the data, these workers made up a third of the local union’s costliest ten per cent of members. To determine if the clinic was really making a difference, the economist compared their costs over twelve months with those of a similar group of Las Vegas casino workers. The results, he cautioned, are still preliminary. The sample was small. One patient requiring a heart transplant could wipe away any savings overnight. Nonetheless, compared with the Las Vegas workers, the Atlantic City workers in Fernandopulle’s program experienced a twenty-five-per-cent drop in costs.

And this was just the start. The program, Fernandopulle told me, is still discovering new tricks. His team just recently figured out, for instance, that one reason some patients call 911 for problems the clinic would handle better is that they don’t have the clinic’s twenty-four-hour call number at hand when they need it. The health coaches told the patients to program it into their cell-phone speed dial, but many didn’t know how to do that. So the health coaches began doing it for them, and the number of 911 calls fell. High-cost habits are sticky; staff members are still learning the subtleties of unsticking them.

Their most difficult obstacle, however, has been the waywardness not of patients but of doctors—the doctors whom the patients see outside the clinic. Jeff Brenner's Camden patients are usually uninsured or on welfare; their doctors were happy to have someone else deal with them. The Atlantic City casino workers and hospital staff, on the other hand, had the best-paying insurance in town. Some doctors weren't about to let that business slip away.

Fernandopulle told me about a woman who had seen a cardiologist for chest pain two decades ago, when she was in her twenties. It was the result of a temporary, inflammatory condition, but he continued to have her see him for an examination and an electrocardiogram every three months, and a cardiac ultrasound every year. The results were always normal. After the clinic doctors advised her to stop, the cardiologist called her at home to say that her health was at risk if she didn't keep seeing him. She went back.

The clinic encountered similar troubles with some of the doctors who saw its hospitalized patients. One group of hospital-based internists was excellent, and coordinated its care plans with the clinic. But the others refused, resulting in longer stays and higher costs (and a fee for every visit, while the better group happened to be the only salaried one). When Fernandopulle arranged to direct the patients to the preferred doctors, the others retaliated, trolling the emergency department and persuading the patients to choose them instead.

“‘Rogues,’ we call them,” Fernandopulle said. He and his colleagues tried warning the patients about the rogue doctors and contacting the E.R. staff to make sure they knew which doctors were preferred. “One time, we literally pinned a note to a patient, like he was Paddington Bear,” he said. They've ended up going to the hospital, and changing the doctors themselves when they have to. As the saying goes, one man's cost is another man's income.

The AtlantiCare hospital system is in a curious position in all this. Can it really make sense for a hospital to invest in a program, like the Special Care Center, that aims at reducing hospitalizations, even if its employees are included? I asked David Tilton, the president and C.E.O. of the system, why he was doing it. He had several answers. Some were of the it's-the-right-thing-to-do variety. But I was interested in the hard-nosed reasons. The Atlantic City economy, he said, could not sustain his health system's perpetually rising costs. His hospital either fought the pressure to control costs and went down with the local economy or learned how to benefit from cost control.

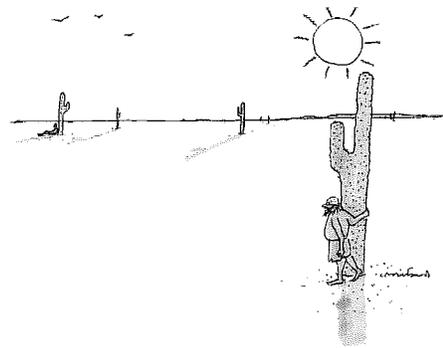
And there *are* ways to benefit. At a minimum, a successful hospital could attract patients from competitors, cushioning it against a future in which people need hospitals less. Two decades ago, for instance, Denmark had more than a hundred and fifty hospitals for its five million people. The country then made changes to strengthen the quality and

availability of outpatient primary-care services (including payments to encourage physicians to provide e-mail access, off-hours consultation, and nurse managers for complex care). Today, the number of hospitals has shrunk to seventy-one. Within five years, fewer than forty are expected to be required. A smart hospital might position itself to be one of the last ones standing.

Could anything that dramatic happen here? An important idea is getting its test run in America: the creation of intensive outpatient care to target hot spots, and thereby reduce over-all health-care costs. But, if it works, hospitals will lose revenue and some will have to close. Medical companies and specialists profiting from the excess of scans and procedures will get squeezed. This will provoke retaliation, counter-campaigns, intense lobbying for Washington to obstruct reform.

*"I said, 'You're starting to get on my nerves!'"*

The stats-and-stethoscope upstarts are nonetheless making their dash. Rushika Fernandopulle has set up a version of his Special Care program in Seattle, for Boeing workers, and is developing one in Las Vegas, for casino workers. Nathan Gunn and Verisk Health have landed new contracts during the past year with companies providing health benefits to more than four million employees and family members. Tim Ferris has obtained federal approval to spread his program for Medicare patients to two other hospitals in the Partners Healthcare System, in Boston (including my own). Jeff Brenner, meanwhile, is seeking to lower health-care costs for all of Camden, by getting its primary-care physicians to extend the hot-spot strategy citywide. We've been looking to Washington to find out how health-care reform will happen. But people like these are its real leaders.



**D**uring my visit to Camden, I attended a meeting that Brenner and several community groups had organized with residents of Northgate II, the building with the highest hospital billing in the city. He wanted to run an idea by them. The meeting took place in the building's ground-floor lounge. There was juice in Styrofoam cups and potato chips on little red plastic plates. A pastor with the Camden Bible Tabernacle started things off with a prayer. Brenner let one of the other coalition members do the talking.

How much money, he asked, did the residents think had been spent on emergency-room and hospital visits in the past five years for the people in this one building? They had no idea. He wrote out the numbers on an easel pad, but they were imponderable abstractions. The residents' eyes widened only when he said that the payments, even accounting for unpaid bills, added up to almost sixty thousand dollars per person. He

asked how many of them believed that they had received sixty thousand dollars' worth of health care. That was when the stories came out: the doctors who wouldn't give anyone on Medicaid an office appointment; the ten-hour emergency-room waits for ten minutes with an intern.

Brenner was proposing to open a doctor's office right in their building, which would reduce their need for hospital visits. If it delivered better care and saved money, the doctor's office would receive part of the money that it saved Medicare and Medicaid, and would be able to add services—services that the residents could help choose. With enough savings, they could have same-day doctor visits, nurse practitioners at night, a social worker, a psychologist. When Brenner's scenario was described, residents murmured approval, but the mention of a social worker brought questions.

“Is she going to be all up in my business?” a woman asked. “I don't know if I like that. I'm not sure I want a social worker hanging around here.”

This doctor's office, people were slowly realizing, would be involved in their lives—a medical professional would be after them about their smoking, drinking, diet, medications. That was O.K. if the person were Dr. Brenner. They knew him. They believed that he cared about them. Acceptance, however, would clearly depend upon execution; it wasn't guaranteed. There was similar ambivalence in the neighborhoods that Compstat strategists targeted for additional—and potentially intrusive—policing.

Yet the stakes in health-care hot-spotting are enormous, and go far beyond health care. A recent report on more than a decade of education-reform spending in Massachusetts detailed a story found in every state. Massachusetts sent nearly a billion dollars to school districts to finance smaller class sizes and better teachers' pay, yet every dollar ended up being diverted to covering rising health-care costs. For each dollar added to school budgets, the costs of maintaining teacher health benefits took a dollar and forty cents.

Every country in the world is battling the rising cost of health care. No community anywhere has demonstrably lowered its health-care costs (not just slowed their rate of increase) by improving medical services. They've lowered costs only by cutting or rationing them. To many people, the problem of health-care costs is best encapsulated in a basic third-grade lesson: you can't have it all. You want higher wages, lower taxes, less debt? Then cut health-care services.

People like Jeff Brenner are saying that we *can* have it all—teachers *and* health care. To be sure, uncertainties remain. Their small, localized successes have not yet been replicated in large populations. Up to a fourth of their patients face problems of a kind they have avoided tackling so far: catastrophic conditions. These are the patients who are in the top one per cent of costs because they were in a car crash that resulted in a hundred thousand dollars in surgery and intensive-care expenses, or had a cancer requiring seven thousand

dollars a week for chemo and radiation. There's nothing much to be done for those patients, you'd think. Yet they are also victims of poor and disjointed service. Improving the value of the services—rewarding better results per dollar spent—could lead to dramatic innovations in catastrophic care, too.

The new health-reform law—Obamacare—is betting big on the Brenners of the world. It says that we can afford to subsidize insurance for millions, remove the ability of private and public insurers to cut high-cost patients from their rolls, *and* improve the quality of care. The law authorizes new forms of Medicare and Medicaid payment to encourage the development of “medical homes” and “accountable care organizations”—doctors’ offices and medical systems that get financial benefits for being more accessible to patients, better organized, and accountable for reducing the over-all costs of care. Backers believe that, given this support, innovators like Brenner will transform health care everywhere.

Critics say that it’s a pipe dream—more money down the health-care sinkhole. They could turn out to be right, Brenner told me; a well-organized opposition could scuttle efforts like his. “In the next few years, we’re going to have absolutely irrefutable evidence that there are ways to reduce health-care costs, and they are ‘high touch’ and they are at the level of care,” he said. “We are going to know that, hands down, this is possible.” From that point onward, he said, “it’s a political problem.” The struggle will be to survive the obstruction of lobbies, and the partisan tendency to view success as victory for the other side.

Already, these forces of resistance have become Brenner’s prime concern. He needs state legislative approval to bring his program to Medicaid patients at Northgate II and across Camden. He needs federal approval to qualify as an accountable care organization for the city’s Medicare patients. In Camden, he has built support across a range of groups, from the state Chamber of Commerce to local hospitals to activist organizations. But for months—even as rising health costs and shrinking state aid have forced the city to contemplate further school cuts and the layoff of almost half of its police—he has been stalled. With divided branches at both the state and the federal level, “government just gets paralyzed,” he says.

In the meantime, though, he’s forging ahead. In December, he introduced an expanded computer database that lets Camden doctors view laboratory results, radiology reports, emergency-room visits, and discharge summaries for their patients from all the hospitals in town—and could show cost patterns, too. The absence of this sort of information is a daily impediment to the care of patients in Boston, where I practice. Right now, we’re nowhere close to having such data. But this, I’m sure, will change. For in places like Camden, New Jersey, one of the poorest cities in America, there are people showing the way. ♦



Atul Gawande, a surgeon and public-health researcher, became a *New Yorker* staff writer in 1998.



# Maine Human Rights Commission

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COMMISSION COUNSEL

## INVESTIGATOR'S REPORT

H14-0500

HUD No. 01-14-0571-8

January 7, 2015

██████████ (Augusta)

v.

██████████ Inc. (Corinth)

### I. Complainant's Complaint:

Complainant ██████████ alleged that Respondent ██████████ discriminated against him on the basis of his mental disability when it involuntarily discharged him from its assisted living facility and refused to let him return to the facility.

### II. Respondent's Answer:

██████████ stated that it did not involuntarily discharge Mr. ██████████ rather, he discharged himself from the facility and did not want to return to the facility.

### III. Jurisdictional Data:

- 1) Dates of alleged discrimination: December 3-14, 2013.
- 2) Date complaint filed with the Maine Human Rights Commission ("Commission"): September 19, 2014.
- 3) Respondents are subject to the Maine Human Rights Act ("MHRA") and the federal Fair Housing Act, as well as state and federal housing regulations.
- 4) Complainant is represented by ██████████, Esq. Respondent is represented by ██████████, Esq.
- 5) Investigative methods used: A thorough review of the written materials provided by the parties and a request for additional information from Respondent. This preliminary investigation is believed to be sufficient to enable the Commissioners to make a finding of "reasonable grounds" or "no reasonable grounds" here.

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IV. Development of Facts:

1) The parties in this case are as follows:

- a) Mr. [REDACTED] has physical and mental disabilities.
- b) [REDACTED] is an 18 bed assisted living facility located in Corinth, Maine.

2) Complainant provided the following in support of his position:

- a) Mr. [REDACTED] physical and mental disabilities include anxiety disorder, post-traumatic stress disorder, and bipolar disorder. He is substantially limited in brain functions, thinking, concentration, focus, and other major life activities including working. Mr. [REDACTED] has a record of mental disability and has been regarded as having a mental disability. He also has physical impairments which cause a substantial limitation in mobility. He uses a wheelchair or a motorized scooter and has a record of a physical disability, and has been regarded as physically disabled.
- b) [REDACTED] was aware of Mr. [REDACTED] disabilities at the time he was admitted to the facility on October 7, 2013.
- c) On December 3, 2013, Mr. [REDACTED] had a phone conversation with Administrator about getting transportation so that he could deposit a check at his bank. Administrator told Mr. [REDACTED] that [REDACTED] would not provide him with special transportation to the bank, and that he would have to wait until a group trip was planned.
  - i. On December 3, 2013, Mr. [REDACTED] was never spoken to by anyone at [REDACTED] regarding their concern for his safety.
- d) On the afternoon of December 3, 2013, Emergency Medical Technicians ("EMTs") came to Mr. [REDACTED] room and told him that Administrator had filed a report claiming he was suicidal. Mr. [REDACTED] told the EMTs that he was not suicidal and had no intention of hurting himself.
  - i. Later law enforcement officers came to Mr. [REDACTED] room and told him that Administrator had called them and told them she wanted him off of the premises. Law enforcement told Mr. [REDACTED] that if he did not leave he would be "blue papered."<sup>1</sup> Mr. [REDACTED] had been "blue papered" about 10 years prior and did not want it to happen again, so he agreed to leave with law enforcement.
- e) Mr. [REDACTED] was taken to the emergency room where he was assessed by a nurse at the hospital ("Nurse"). Nurse determined that Mr. [REDACTED] was not a danger to himself or others and contacted Administrator to find out about Mr. [REDACTED] return to [REDACTED]

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<sup>1</sup> Being "blue papered" is short hand for the procedure to involuntarily commit an individual to a psychiatric hospital on an emergency basis.

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- f) Administrator told Nurse that Mr. [REDACTED] was not coming back to [REDACTED]
- g) On December 13, 2013, Mr. [REDACTED] attorney informed Administrator by letter that Mr. [REDACTED] had not discharged himself from [REDACTED] and that doctors had cleared him medically and psychiatrically to return to [REDACTED]
- h) On or about December 14, 2014, Administrator told Mr. [REDACTED] attorney that she had filled Mr. [REDACTED] bed at [REDACTED] and that he was not allowed to return to the facility.
- i) [REDACTED] brochure states: "Unlike most other facilities our rates don't go up as your condition declines. Also, you are not at risk of having to move merely because your condition declines, ensuring you or your loved one can truly 'age in place.'" (Emphasis in original.)
- j) Mr. [REDACTED] appealed to the Maine Department of Health and Human Services ("DHHS") regarding [REDACTED] decision to not allow him to return to the facility.<sup>3</sup> A DHHS hearing was held on January 13, 2014, at which the following exchange occurred:

Mr. [REDACTED] attorney: "If Mr. [REDACTED] condition declined because you thought he was suicidal he wouldn't be require to move, is that right?"

Administrator: "He would need placement, we're not a mental health facility if that's what you're asking me. We take care of mostly geriatric patients meaning if they have strokes we don't send them away we keep them, that's why we took him in a wheelchair."

- k) Also during the DHHS hearing Administrator testified that the sole reason that she did not consider Mr. [REDACTED] request for readmission was his mental health history.<sup>4</sup>
- l) The DHHS hearing officer's ruling regarding Mr. [REDACTED] appeal (the "Decision") provided the following information:
  - i. During his residency at [REDACTED] Mr. [REDACTED] had been admitted to the hospital for physical problems and returned to [REDACTED] after discharge from the hospital.
  - ii. On December 2, 2014, Mr. [REDACTED] told the Resident Coordinator that he intended to pack his belongings and move out of [REDACTED]. The Resident Coordinator told Administrator and the Medical Care Provider what Mr. [REDACTED] had told her.

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<sup>2</sup> Administrator stated that she thought Mr. [REDACTED] wanted to discharge himself.

<sup>3</sup> In his DHHS hearing, Mr. [REDACTED] characterized what happened to him as an involuntary emergency discharge. In response to Mr. [REDACTED] claim, [REDACTED] stated that Mr. [REDACTED] voluntarily discharged himself from the facility.

<sup>4</sup> The investigator's reliance on the DHHS transcript in this report relates only to the facts/testimony presented by the parties in that proceeding. The transcript is not being relied on for its ultimate decision as it is separate and apart from the Commission's purpose of determining if there is, or is not, reasonable grounds to find that discrimination occurred.

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- iii. Administrator and the Medical Care Provider are responsible for preparing discharge paperwork which includes an inventory sheet and a discharge sheet explaining the reason for a resident's discharge. The inventory sheet is started when a resident is admitted and lists the resident's belongings at the time he/she is admitted. The sheet is completed when the resident is discharged.
- iv. Administrator advised Mr. [REDACTED] that it would be good for [REDACTED] to arrange a Good Health Systems evaluation to assess Mr. [REDACTED] eligibility for MaineCare reimbursement for various levels of care before he left [REDACTED]. The assessment was scheduled for December 5, 2013.
- v. On December 3, 2014, Mr. [REDACTED] was upset because one of the doctors discontinued one of his ADHD medications without consulting with Mr. [REDACTED]. Mr. [REDACTED] informed one of the Certified Registered Medication Aides ("CRMA") that he was going to find a taxi and motel that accepted debit cards. Mr. [REDACTED] stated, "I'll go to a motel and if God takes me, it's His will." The CRMA understood Mr. [REDACTED] comments as indicating his intent to commit suicide, so she told Administrator who contacted EMTs as well as the State Police.
- vi. At first Mr. [REDACTED] was not cooperative with the EMTs or State Police, but he was eventually persuaded to allow EMTs to transport him to the hospital after he was told that the alternative would be to seek involuntary psychiatric hospitalization for him.
  - i. The EMTs and State Police requested and received boxes from [REDACTED] which they filled with items at Mr. [REDACTED] direction. State Police photographed the remaining items in Mr. [REDACTED] room, including Mr. [REDACTED] wheelchair and slide board.
- vii. The hospital's discharge summary for Mr. [REDACTED] dated December 13, 2013, stated, "... was called to evaluate the patient [Mr. [REDACTED]]. They did not feel that he will require any voluntary or involuntary psychiatric facility placement. He was not showing any signs of depression or psychosis. No suicide or homicide ideation... the patient is medically free to be discharged and it was stated clearly by an order that was put in patient's charge on 12/6/13 [healthcare provider], patient not at observation level of care, nor the acute level of care, nor the skilled level of care..."
- viii. [REDACTED] never began or completed discharge paperwork for Mr. [REDACTED] and a discharge notice was never issued.

3) Respondent provided the following in response to Complainant's allegations:

- a) During Mr. [REDACTED] first month at [REDACTED] both Mr. [REDACTED] and [REDACTED] appeared to assess the relationship as going well. Mr. [REDACTED] was sent to the emergency room on October 21, 2013, due to an apparent seizure. After his seizure, [REDACTED] observed him to be more needy/demanding.

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- b) Administrator spoke to Mr. [REDACTED] about his outbursts of attention-seeking behavior. At one point in November, 2013, Mr. [REDACTED] stated that he was packing and leaving after Administrator told him that his behavior was becoming totally unreasonable and inappropriate. At the time, Administrator told Mr. [REDACTED] that she would assist him in finding another placement. Administrator later contacted Mr. [REDACTED] and told him that she had found two openings for him. He replied that he had spoken to his mom and she had talked him into staying at [REDACTED]
- i. Administrator told Mr. [REDACTED] that if he was going to continue being overly critical of staff and other residents he should consider moving, because she did not want him to be unhappy or make others unhappy. Mr. [REDACTED] apologized for his behavior and said that he was not normally difficult to deal with. Administrator told him that she would give it another try and appreciated his cooperation.
- c) On November 19, 2013, Mr. [REDACTED] was sent to the emergency room for chest pains and came back that same evening. Mr. [REDACTED] became more demanding after this visit to the emergency room.
- d) In the DHHS hearing (as recorded on the transcript), employees of [REDACTED] who were involved with the situation with Mr. [REDACTED] stated that no employee of [REDACTED] assisted Mr. [REDACTED] in packing or indicated to him that they wanted him out of the facility. The Resident Coordinator and/or Administrator at one point tried to convince Mr. [REDACTED] to stay at [REDACTED] so that an assessment could be conducted to determine a proper placement for Mr. [REDACTED] which he voluntarily sought.
- i. [REDACTED] stated that Mr. [REDACTED] packed up his own belongings and his mom was going to pick up the things he could not take with him.<sup>5</sup> Administrator spoke to the Medical Care Provider because Mr. [REDACTED] stated he was leaving so the Medical Care Provider could make some recommendations about Mr. [REDACTED] medications since he was leaving the facility.
- e) Once Mr. [REDACTED] made suicidal statements<sup>6</sup> and threatened employees of [REDACTED] for interfering with his medication, [REDACTED] felt it was appropriate for it to discharge Mr. [REDACTED] from the facility under the rules and regulations and guidelines of the facility and the State.
- i. [REDACTED] was concerned about the safety of Mr. [REDACTED] and others at the facility. Administrator is a registered nurse and is legally obligated to contact EMTs if she comes to the reasonable conclusion that some might be suicidal.
- f) Nurse testified in the DHHS hearing that Mr. [REDACTED] refused to return to [REDACTED] when he was in the emergency room. She also testified that she felt Mr. [REDACTED] had given her the impression that he was not wanted to [REDACTED]
- i. Nurse further testified that she was under the assumption that Mr. [REDACTED] had not packed his own boxes and had been forced to leave [REDACTED] Nurse also testified that on more than

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<sup>5</sup> Mr. [REDACTED] had shown a nurse that day that he cleaned out his drawers, and he was all packed up.

<sup>6</sup> During the hearing, a nurse testified that Mr. [REDACTED] told her that he was going to a hotel to kill himself.

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one occasion she had seen some patients returned to [REDACTED] after going to the hospital and others did not. Nurse agreed that if a patient did not want to go back to a facility, it would be a violation of his/her rights for the hospital to force that person to go back to the facility they had come from.

- ii. When Administrator spoke to Nurse while Mr. [REDACTED] was in the hospital, she learned that Nurse was not calling to inquire about whether [REDACTED] would readmit Mr. [REDACTED] but was calling to find out about Mr. [REDACTED] wheelchair. Nurse told Administrator that Mr. [REDACTED] was not coming back to the facility.
  - g) Mr. [REDACTED] residency at [REDACTED] was not terminated by the facility. Mr. [REDACTED] voluntarily left [REDACTED] and he only asked to be returned there after he was not able to be placed in a new facility on or before December 13, 2013. By the time Mr. [REDACTED] attorney contacted [REDACTED] the bed had been filled.
  - h) Respondent is not a mental healthcare facility. The language in the brochure refers to the decline in a "physical" condition of a patient.
  - i) Residential Coordinator testified in the hearing that Mr. [REDACTED] left before discharge papers could be prepared. Administrator also testified that a discharge summary was prepared contemporaneously.
  - j) Mr. [REDACTED] was not allowed readmission to [REDACTED] but he was also denied admission to other facilities as well. [REDACTED] believed this was due to his behavior.<sup>7</sup>
  - k) Mr. [REDACTED] was denied readmission to [REDACTED] due his mental health history as well as the fact that he "made a voluntary discharge and threatened others."
  - l) In the past five years, there was a discharge somewhat similar (but not exactly similar) to that of Mr. [REDACTED]. A 90 year old resident threatened her roommate on numerous occasions and was involuntarily discharged. DHHS found in that instance that the resident could properly be discharged.
  - m) While Complainant may have some level of mental impairment, Complainant is capable of making substantial life decisions, including decisions about where he wants to live or whether he could voluntarily discharge himself from any facility where he is housed.
- 4) The Contract for services signed by Mr. [REDACTED] and [REDACTED] provides that, "... if [the resident's] needs exceed [REDACTED] ability to provide services, [REDACTED] will assist [the resident] in making other arrangements including moving somewhere else, if necessary."
  - 5) The Contract also provides that [REDACTED] will help Mr. [REDACTED] arrange transportation but costs of transportation are not included in this assistance.

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<sup>7</sup> In the hearing transcript Administrator testified that Mr. [REDACTED] told her that he had 10 other prior placements and no one would take him back after he left [REDACTED]

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- 6) The Contract states that residents' rights related to discharge are attached at Appendix B, but there was no Appendix B attached to Respondent's submission.<sup>7</sup>
- 7) The following exhibits are attached to this Report:
  - a) Exhibit 1: nursing notes related to Mr. [REDACTED] residency at [REDACTED]
  - b) Exhibit 2: pre-treatment and during treatment hospital notes for Mr. [REDACTED]
  - c) Exhibit 3: transcript of a voice mail message from Administrator to Mr. [REDACTED] attorney.
  - d) Exhibit 4: [REDACTED] discharge policy.
- 8) The nursing notes for December 3, 2013, stated that the EMTs who showed up for Mr. [REDACTED] had to wait outside for law enforcement, which is their standard practice. The pre-hospital notes from the EMTs that dealt with Mr. [REDACTED] state that [REDACTED] director wanted the EMTs to stay outside until law enforcement showed up.
  - a) During the hearing, Administrator testified that she thought this part of the pre-hospital notes was false because she did not stop the EMTs from entering the facility without law enforcement.
  - b) The notes also state that "the state trooper states that the [Administrator] does not want [Mr. [REDACTED] there anymore". The transcript of the hearing shows that Administrator clarified her statement to mean that she did not want him there anymore because he was suicidal. Administrator further stated that Mr. [REDACTED] was leaving [REDACTED] on his own, but when he became suicidal she had to call and intervene because she was afraid he would hurt himself.
- 9) The hearing transcript reflects that Administrator stated that when someone decides to leave the facility, [REDACTED] does not just immediately say you have to leave.
- 10) Administrator began placing calls to fill Mr. [REDACTED] bed the day he told [REDACTED] he was leaving.
- 11) Respondents did not provide any documentation showing that Mr. [REDACTED] had a prior history of being suicidal.

V. Analysis:

- 1) The MHRA provides that the Commission or its delegated investigator "shall conduct such preliminary investigation as it determines necessary to determine whether there are reasonable grounds to believe that unlawful discrimination has occurred." 5 M.R.S. § 4612(1)(B). The Commission interprets the "reasonable grounds" standard to mean that there is at least an even chance of Complainant prevailing in a civil action.

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<sup>7</sup> Respondent provided its discharge procedures as part of a request for additional information.

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- 2) The MHRA provides, in part, that any person has the right to rent or lease a housing accommodation or partake in the facilities or services of a housing accommodation without discrimination on the basis of disability. 5 M.R.S. § 4581-A(1)(D); 94-348 CMR. Ch. 8, § 8.04(a)(3).
- 3) The MHRA also provides, in part, that it is "unlawful for a person to coerce, intimidate, threaten or interfere with any individual in the exercise or enjoyment of the rights granted or protected by this Act", 5 M.R.S. § 4633(2), or to "evict... any tenant of any housing accommodations because of physical or mental disability." 5 M.R.S. § 4581-A(1)(E).
- 4) The Commission's housing regulation, which interprets § 4633(2), provides that:
  - A. It shall be unlawful to coerce, intimidate, threaten, or interfere with any person in the exercise or enjoyment of, or on account of that person having aided or encouraged any person in the exercise or enjoyment of, any right granted or protected by this part.
  - B. Conduct made unlawful under this section includes, but is not limited to...
    - (2) Threatening, intimidating or interfering with persons in their enjoyment of a dwelling because of the race or disability... of such persons...

94-348 C.M.R. Ch. 8, § 8.09.

- 5) Here, Complainant alleged that he was discharged/evicted from his housing facility and denied readmittance and the ability to "age in place" on the basis of his mental disability. Respondent stated that Complainant voluntarily discharged himself and that it had had filled his bed by the time he asked to be readmitted to the facility.
- 6) Because the disability discrimination claim does not involve direct evidence<sup>8</sup>, Complainant establishes a prima-facie case of unlawful housing discrimination with respect to his eviction by proving (1) he was a member of a class protected under the MHRA; (2) Respondent was aware of his membership in that class at the time of the eviction; (3) he was willing and qualified to continue the housing accommodation; and (4) Respondent refused to permit him to continue the housing accommodation. See *Radecki v. Joura*, 114 F.3d 115, 116 (8th Cir. 1997).
- 7) Complainant establishes a prima-facie case of unlawful housing discrimination with respect to being refused readmission<sup>9</sup> to the housing accommodation by proving (1) he is a member of a protected class; (2) he applied for and was qualified to live at [REDACTED] (3) that Respondent rejected him for admission;

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<sup>8</sup> Complainant argues that Administrator's testimony at the DHHS hearing ("When the hospital said would you ever consider a readmission, I said no based on his mental health history") was itself direct evidence of discrimination. We do not decide here that it is, or is not, direct evidence; instead, we utilize the traditional burden-shifting analysis.

<sup>9</sup> Complainant also alleged that he was not allowed to "age in place" due to his mental disability. Because this claim is, in essence, identical to the claim that Respondent would not readmit him – which had the effect of denying him the opportunity to "age in place" – this claim is not analyzed separately, but is considered part of the readmission issue.

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and (4) that the housing accommodation remained available thereafter. *See United States v. Grishman*, 818 F. Supp. 21, 23 (D.Me. 1993); *HUD v. Blackwell*, 908 F.2d 864, 870 (11<sup>th</sup> Cir. 1990).

- 8) Once Complainant has established a prima-facie case, the burden of production, but not of persuasion, shifts to Respondent to articulate a legitimate, nondiscriminatory reason for its action. *See United States v. Grishman*, 818 F. Supp. at 23; *HUD v. Blackwell*, 908 F.2d at 870; *Doyle v. Dep't of Human Servs*, 2003 ME 61, ¶ 15, 824 A.2d 48, 54. After Respondent has articulated a nondiscriminatory reason, Complainant must (to prevail) demonstrate that the nondiscriminatory reason is pretextual or irrelevant and that unlawful discrimination brought about the adverse housing action. *See id.* Complainant's burden may be met either by the strength of Complainant's evidence of unlawful discriminatory motive or by proof that Respondent's proffered reason should be rejected. *See Cookson v. Brewer School Department*, 2009 ME 57, ¶ 16; *City of Auburn*, 408 A.2d at 1262, 1267-68. Thus, Complainant can meet his overall burden at this stage by showing that (1) the circumstances underlying the articulated reason are untrue, or (2) even if true, those circumstances were not the actual cause of the decision. *Cookson v. Brewer School Department*, 2009 ME 57, ¶ 16.
- 9) In order to prevail, Complainant must show that he would not have suffered the adverse action but for membership in the protected class, although protected-class status need not be the only reason for the decision. *See Maine Human Rights Comm'n v. City of Auburn*, 408 A.2d 1253, 1268 (Me. 1979).
- 10) Complainant has stated a prima-facie case of discrimination based on disability both with regard to his eviction and with regard to the refusal to readmit him. Complainant has shown that he was a member of a protected class, Respondent was aware of his disability, Complainant was qualified and willing to continue staying at the facility, and Respondent refused to allow him to continue to stay at the facility. With regard to Complainant's efforts to return to the housing, Complainant was eligible for the housing and was rejected, while a bed may have been available.
- 11) Respondent has stated a legitimate non-discriminatory reason for Complainant's discharge and its decision not to readmit him: Complainant voluntarily discharged himself and was not readmitted because of his behavioral issues and his bed was already filled when he sought to return to the facility.
- 12) At the final stage of the analysis, Complainant has demonstrated at least an even chance of success in a lawsuit and that Respondent's reason for the adverse housing action was pretextual and/or irrelevant, with reasoning as follows:
  - a. The record in this case shows that Complainant stated he was going to leave the facility on at least one prior occasion while he was a resident at Respondent's facility. In the prior instance, Respondent researched other placement opportunities for Complainant and communicated his options to him, but Respondent did not start discharge paperwork for Complainant. Complainant ultimately decided that he was going to stay at the facility.
  - b. In contrast, during the days leading up to Complainant's discharge in December 2013, Complainant again indicated that he was planning to leave the facility. In this instance, Respondent did provide documentation to show that a discharge summary had been started for Complainant, but it did not follow its express discharge policies and procedures with Complainant. It is not at all clear prior to December 3, 2013 that Respondent was in the process of discharging Complainant.

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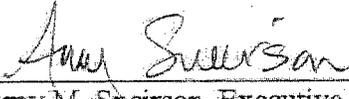
- c. The evidence here does support Respondent's claims that Complainant had indicated his desire to leave the facility, but it is clear he did not leave on his own accord; it was Respondent's actions that forced him to leave the facility. Even though Administrator discharged Complainant after he was told he had to leave with EMTs and law enforcement or be "blue papered", Respondent disputed in the DHHS hearing that Complainant was discharged from the facility under emergency circumstances. This is not persuasive.
- d. Administrator stated in the DHHS hearing transcript that Complainant had expressed suicidal ideations in the past, and that his history, his December 3, 2013 expression of suicidal ideation, and his mental health were among the reasons he was taken from the facility on December 3, 2013, and then denied readmission to the facility. While Complainant may have been a difficult resident, the record does not reflect or show that Complainant had past suicidal ideations. In particular there is no mention of past suicidal ideations in the nursing notes provided by Respondent, and Respondent did not provide additional documentation related to past incidents of Complainant's suicidal ideations.
- e. Complainant did not leave the facility on his own terms, and was forced to leave in part due to his mental disability. Complainant did not have or get a chance to come back. Further, Respondent's actions in not following its own discharge policies and the changing classification of Complainant's departure from the facility creates pretext.
- f. Respondent had admitted Complainant to its facilities with the knowledge of his disabilities, but it appears that Respondent effectively changed its mind once Complainant's disabilities became more pronounced. It also appears that Administrator's decision to discharge Complainant and refuse to allow him to return was influenced by his mental disability. Administrator testified to the effect that while individuals with physical disabilities would not be removed from the facility, the promise to "age in place" did not apply to mental disabilities. Respondent's decisions here – to remove Complainant involuntarily without following its own discharge processes, and to not allow him to return – were influenced by Complainant's mental disability.
- g. The fact that Complainant had notified Respondent of his intention to leave remains a factual hurdle for Complainant; based on the record, however, Complainant has shown that he has at least an even chance of success in a lawsuit.

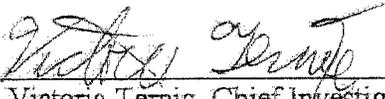
13) Disability discrimination in housing is found.

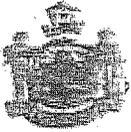
**VI. Recommendation:**

For the reasons stated above, it is recommended that the Maine Human Rights Commission issue the following findings:

There are **Reasonable Grounds** to believe that Respondent [REDACTED] Inc. discriminated against Complainant [REDACTED] in housing on the basis of disability, and conciliation should be attempted in accordance with 5 M.R.S. § 4612(3).

  
\_\_\_\_\_  
Amy M. Sheirson, Executive Director

  
\_\_\_\_\_  
Victoria Ternig, Chief Investigator



Maine Human Rights Commission  
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MAR 02 2015

Barbara Archer Hirsch  
COMMISSION COUNSEL

Amy M. Sneirson  
EXECUTIVE DIRECTOR

February 27, 2015

Disability Rights Center  
Mark C Joyce Esq  
24 Stone Street Ste 204  
Augusta, ME 04330

RE: STATEMENT OF FINDING -  
H14- [REDACTED]

Dear Mr. Joyce

The Commission has conducted an investigation of the above complaint of discrimination and has determined that there are reasonable grounds to believe that unlawful discrimination has occurred. The decision was based on information received during the course of investigation of the complaint including the Investigator's Report, any written submissions, and any oral presentations made.

Pursuant to §4612(3) of the Maine Human Rights Act, the Commission will endeavor to resolve the reasonable grounds determination. Both parties will be contacted by the Commission's Compliance Officer to discuss resolution of this matter. If no settlement is reached, the Maine Human Rights Act authorizes the filing of a civil action in Superior Court.

It is important to note that all information relating to the conciliation process is confidential without the written consent of all parties. The Maine Human Rights Act provides that you may pursue this matter on your own.

We hope that an amiable resolution can be achieved.

Sincerely yours,

Amy M. Sneirson  
Executive Director

**DECISION:**

- A. [REDACTED] was involuntarily discharged from [REDACTED], on or about December 3, 2013.
- B. [REDACTED], was not correct according to the Regulations Governing the Licensing and Functioning of Assisted Housing Programs in discharging [REDACTED] on or about December 3, 2013.

# Home, Hope and Healing, Inc.

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Hearing LD 155

Good afternoon Senator Brakey, Representative Gattine and the distinguished members of the Health and Human Services Committee. My name is Jill Lufkin Robinson and I am from Oakland, ME. I am here to support LD 155 a conceptual bill that would improve housing options for Maine residents who have complex medical conditions such as severe head trauma or are ventilator dependent.

My sister, Jane Greenblatt and I started Home, Hope and Healing, Inc. nearly 13 years ago. It is a home care company that specializes in the treatment of medically complex children and adults throughout the state of Maine. Over the years, we have cared for scores of medically complex cases who have come home directly from Intensive Care Units across Maine and New England. During those years we have taken care of dozens of ventilator dependent clients and when necessary have helped them find placement when their families could no longer care for them. Sadly a number of our consumers have elected to come off the ventilator and die rather than go into a facility or have their family continue to bear the burden of their care. We provide almost exclusively skilled nursing, RN, LPN services under section 96 of the MaineCare manual, to consumers in need of complex medical care in their homes. This program is called Private Duty Nursing and meets the needs of clients with 24/7 medical care requirements. This program has a predetermined maximum monthly cap of 20,682/individual. The consumer must meet strict medical criteria in order to qualify for this program such as ventilator dependence. That is not the tough part. In order to qualify for this PDN level V service, they must also have a place of residence and family support that can meet their needs (a contingency for care) in the absence of nursing staff. Here-in lies the problem for many of these Maine residents. Without a contingency of care, home skilled nursing is not a viable option. Facilities such as hospitals and skilled nursing homes become their only choice.



We believe Maine can build on a service that is already in place by combining Private Duty Nursing, Section 96, with a housing option that includes a contingency for skilled care. Instead of sending these residents out-of-state for their care as is the current practice, we believe it is in the best interest of Mainers to care for them here in Maine. Not only will this keep Maine Residents here close to friends and families, but it will create jobs and provide a revenue base through taxes for the State. We believe there will also be a significant cost savings to the State. Instead of sending our Maine and Federal dollars for PDN care out of state we will keep those dollars in state. By doing this we can take advantage of Maine's Section 96 multi-client rate which allows providers to provide nursing services to 2 clients and bill out at a reduced rate. See attached rates.

We propose the housing be offered in small residences where each client would rent a room and would have the feel of a non-facility setting. The home could house 3-6 residents. Skilled nursing services would be provided around the clock under section 96 funding. Each of the residents would be responsible for their monthly rent/living expenses which could be paid through their monthly Medicare checks or other means.

Maine currently has 110 patients in hospitals every day who have nowhere to go except to out-of-state facility settings. A number of clients from hospitals have already been sent out of state to facilities both in NH and MA. This is not a problem that will resolve itself. As technology increases and life spans are extended, we are seeing an increase in the need for complex care outside of a hospital or skilled unit setting. This is a growing need throughout the country. Maine has the opportunity of creating a new model of care that combines its current programs with a new housing option. We have the opportunity to set the standard of home care for this medically complex population and to be leaders in solving this challenging national concern.

To summarize, we can take care of Maine residents with complex medical needs here in Maine outside of hospitals. This can be done by combining a housing option with a current MaineCare program, Section 96 Private Duty Nursing. By



keeping these vulnerable citizens in Maine, we care for our own, save money, create jobs and increase tax revenues. We believe their quality of life would be greatly enhanced in this home-like setting and that Maine could become a leader in finding solutions for this growing population.



## Questions regarding proposed "Vent House"

1. What types of nursing services are being proposed for the patients who reside there (RN, LPN, CNA, Respiratory Therapy)? It is planned that there will be a 2:1 ration of 2 patients to 1 skilled nurse for both the day and night shifts. If an LPN is utilized, they will work with an RN. The day shift would also have PSS support to provide for IADL needs such as grocery shopping, cooking, cleaning and running needed errands.
2. What will be the staffing pattern/proposal (ratios)? 2 clients/nurse
3. What is the anticipated length of stay for the patients? These are LTC patients that may live in the residence until they die or choose another location for their care.
4. Who will be residing/living in the building (patient, family, staff)? Only patients will live in the residence. It will be staffed 24/7 with a 24/7 on-call system as a backup to unforeseen events.
5. What is the proposed room lease? The lease will vary depending on income and ability to pay by providing a sliding scale based upon income. We are making all the changes necessary for patients to be able to access section 8 housing for those with medical handicaps. The lease will also depend on the size and location of the room. Two are larger and more private and may attract private pay clients.
6. What additional services will be provided (Dietary, laundry, housekeeping, pharmacy and medical gas, maintenance)? Meal preparation, laundry, housekeeping and maintenance will be provided as part of their rent. Medical gas will be provided by each patient's respiratory vendor.
7. What is the arrangement for physician services and 24-hour emergency coverage? Each patient will have a POC developed by an RN in coordination with the patient's primary physician. An on-call RN is available to answer staff's concerns and 911 will be assessed for 24/7 emergencies
8. What are the expected patient limitations? They will be totally dependent on all ADLs and bedbound or wheelchair bound. They may be able to function off their ventilators for periods of time. Some others will be totally dependent. They will be transferred via hoists which are supplied by their DME providers as will be their hospital beds. All of their supplies will be ordered through their DME and kept separately in storage areas in their rooms.
9. What is the proposed equipment maintenance program – especially related to the ventilators? The equipment will be owned by



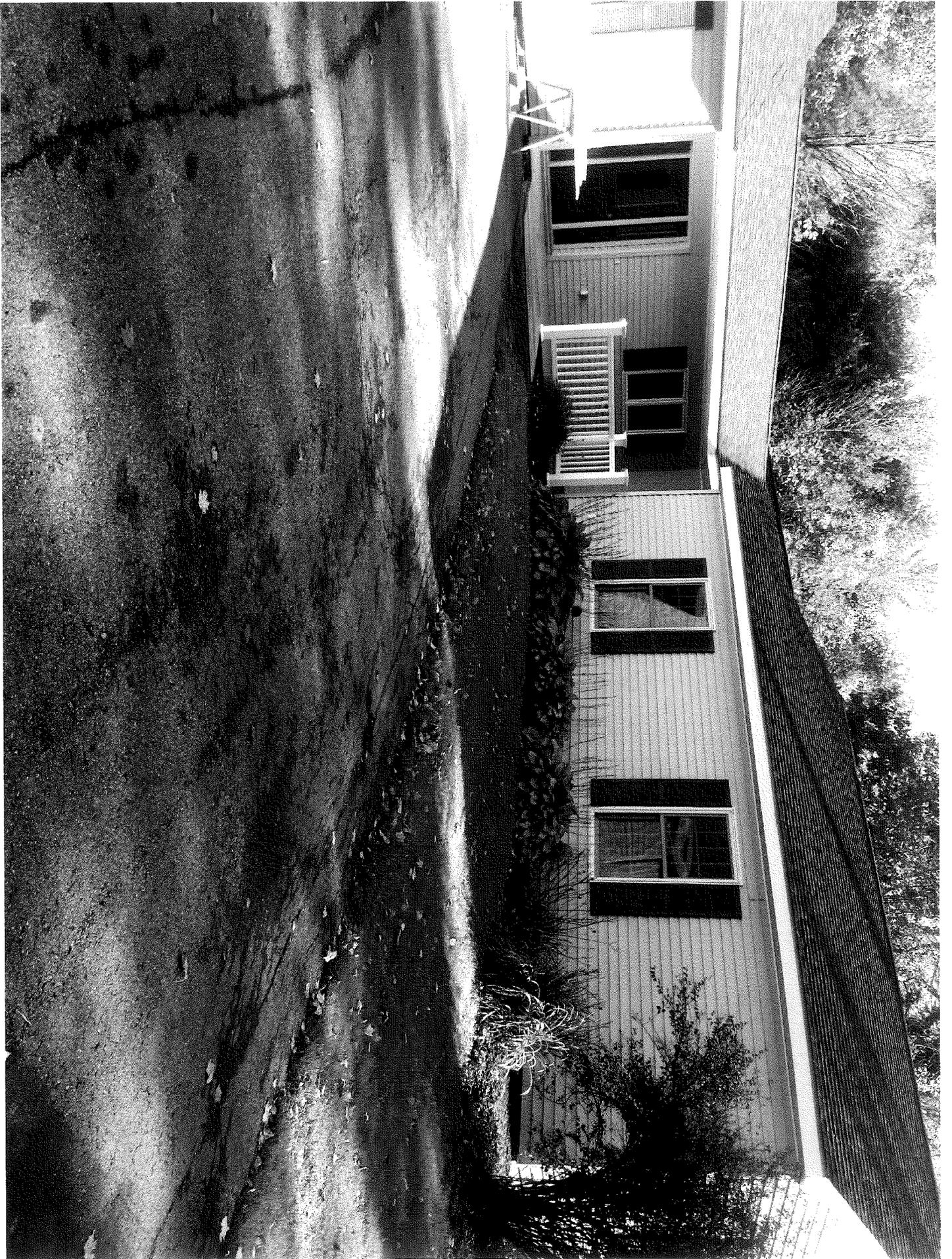
the respiratory vendors and serviced by them just as they are done in a private residence. We have spoken with one national company that we work closely with and they are pleased about the prospect of having a place for the patients to go and are looking forward to working with us in this setting.

10. What is the physical plant proposal in regards to Life Safety code requirements for protection in place, emergency power, call system and floor plan? We will be working with the Fire Safety Marshall as we get closer to completion. We are installing an emergency generator that will power the entire residence. We are adding two exits to the two bedroom which are the furthest from the other 3 exits. They will be wide doors that can accommodate rolling the beds out onto a deck with ramp for swift evacuation should there be a fire. The two other rooms are close to exits with disability access. The generator will come on immediately and automatically should power be lost. There will be two stretchers available near the other two bedrooms should evacuation be necessary. There are hard wired smoke alarms and 3 fire extinguisher located throughout the residence. Fire drills with timed evacuations will be part of safety program as directed by fire marshall.
11. What is the plan for infection control? Waterless hand cleansing dispensers will be located in each client room, and in the living spaces. The three sinks will have aseptic cleansers and towel dispensers readily available. Standard Precautions will be followed for each patient and PPE equipment will be available for all staff. Equipment care will be according to the vendors recommendations just as it would be in any other residence.
12. What is the proposal for administration and management oversight? This vent house is 10 minutes from HHH's main office and its administrator and Director of Clinical Services will oversee its management. A team leader will be chosen to administer the day-to-day functions when the staff is hired for the house. As this is a new venture and new model of care, we will be very involved to assure its success and that the client's receive safe, effective, high quality care. There is a large training room in the finished breezeway between the main house and the garage. HHH staff will receive training there which will bring agency administration staff frequently to the vent house.













October 26, 2015

**RE: Testimony to LD 155 Commission (Expanded Comments)**

Thank you, Senator Katz, Representative Gattine, Representative Malaby, as the bill sponsor and members of the Commission, for receiving our comments on this important piece of legislation. My name is John Gregoire, and I'm here with my lovely wife and caregiver, Linda. We live in Windham, Maine. We are Co-Founders of The Hope-JG Foundation which, among other things, is dedicated to building a world class, ALS/MS Residence in Maine. We are here to ask you to ensure that neurodegenerative diseases remain included in the final version of this bill. I know it's been a long day for everyone, and time is running short. I'll make some brief comments, out of respect for everyone's time. You'll also find an expanded version of my comments, as well as information regarding our foundation, in the red packets we've handed out.

It may not look it from my stunning appearance, but you are looking at a dying man. I have ALS, for which there is no cure. The Doctor who gave us the definitive diagnosis said, without question, I had 18 months to live. That was in December of 2007. Maybe the Doctor was just wrong. But, I think. Check that. I know, it's because I've had the benefit of a loving caregiver and advocate, in my lovely wife, the best nutrition, which we had to fight for, (I have a feeding tube, so I rely on a formula and we found the world's only, whole food, organic, formula). And, we've been blessed to find the best technology and clinicians available for communication, to keep me socially engaged. That, is what our residence for ALS and MS patients will provide, and that's only phase one, but, we have to start somewhere, right?

Our vision to build a world class ALS, MS Residence in Maine is a daunting task. It is also a vital one. There are currently, no long term care facilities in Maine willing to take patients with ALS - particularly patients who are ventilator dependent. That may have changed, since the recent increase in reimbursement rates. However, from what we've heard in our discussions with operators and managers of nursing homes, I don't think so. Care of ALS patients is just too labor intensive for a traditional nursing home. Just ask my wife how intense my care is, even with help. The families of those who do choose to ventilate, but can't care for them at home, are faced with the heart wrenching decision to send their loved one out of state. For this reason, many patients with ALS, who could continue to live productive lives, choose not to vent. And those people soon die. ***We aim to change that heartbreak into hope.*** We know many people, with neurodegenerative disease across the country, who are being cared for, at home, and in residential settings such as we will build, who are tutoring, making films, and even skydiving. All because they have found clinicians and administrators, who didn't view them as liabilities.

There is information in your packets that tells a bit about the “how” we plan to fund and build a world class ALS/MS Residence in Maine. We are in the final stages of shaping a capital campaign for construction and to create an endowment for operating costs, over and above what insurance will pay. The funding, financial feasibility, bricks and mortar are all achievable, if this body has the fortitude to enact this legislation. Francis Bacon said: "Fortitude is the marshal of thought, the armor of the will, and the fort of reason." I have confidence that this Commission, as a group, reflects those attributes, because you, represent the best of Maine. We believe Maine can, as it has done before, lead the nation by showing how we take care of our own. That Maine can show the world that we embrace innovation as a way of honoring and enabling our afflicted neighbors, rather than warehousing them, or worse, rushing them into hospice.

Our foundation has identified six Innovators from as far away as Lisbon, Portugal, who have developed disruptive technologies, products or services which can enhance the lives of the disabled. Notice I used the word "disabled", not just "ALS". Our primary goal is getting a first, fully automated, Green House Certified, ALS/MS Residence up and running in Maine. We plan using these products and services, as appropriate in our residence. However, through our Innovator initiative we will develop a global reach by nurturing disruptive innovations which can benefit people around the world suffering the ravages of a host of afflictions. We believe the additional touch points we will continue to create with a broad spectrum of disease groups will enable our foundation to help more people in Maine and around the world. By identifying innovative products like Liquid Hope, (which we mentioned earlier). Liquid Hope is the world's only certified organic, non-GMO, sugar, gluten and soy free, whole foods enteral feeding formula. We believe we can improve the health of patients with a spectrum of diseases who require enteral nutrition. We can also save the people of Maine and Health Insurers valuable dollars by avoiding the often under reported complications inherent with commonly prescribed, sugar, soy and chemical laden commercial formulas.

There are other great success stories within our Innovator "family". The first version of Eyespeak, a pair of augmented reality eye glasses on which a speech impaired person can type on a virtual keyboard using their eyes (regardless of their head position) and which will "speak" what is typed, has been delivered. (And, Eyespeak is about \$13,000 less than currently available Medicare approved Speech Generating Devices.) Another Innovator from Brown University, is making eye tracking devices for people from cheap, easy to procure parts for as little as \$30. Still another, from Sheffield University in the UK, is finishing final field trials of a cloth, fully customizable neck brace specifically for people with neurodegenerative disease. I've had the fortune to try it and it's a stunningly elegant and effective design. And finally, there is VocaliD (pronounced: *vocality*), started by Dr. Rupal Patel of Northeastern University. VocaliD gives back a unique identity to speech impaired people who use synthetic voices to communicate now. There are currently about 20 synthetic voices used by over 3.5M people worldwide – so many people slung the same, regardless of age, build or even gender.

More important than the “how” we will do this is the “why” At any given time, Maine has approximately 90 ALS patients and their families, battling this still incurable (and financially devastating) disease. Our state also has a significantly higher rate of MS than the national average. Maine also has a significant lack of neurologists who are not experienced or specialized in the latest therapeutic, holistic or technical advances which can enhance, and extend the lives of patients afflicted with this family of rare neurodegenerative diseases.

The "why" is because we should. The "why" is because we can. The technology and new, patient centered care models are out there. Vented, and non-vented ALS and MS patients *can* live quality lives. We owe them the same opportunity that other difficult to place patients will get. A private/public partnership, is the way to do it. Notice, I put "private" in front of "public". That was by intent. The people, corporations, and private foundations of Maine, can and will do this, if this Commission only paves the way.

We are more than happy to speak with any Commission members separately, or, to return to address the Commission as a body.

Thank you for your time.

John A. Gregoire  
Co-Founder  
The Hope-JG Foundation

**ADDENDUM A**  
**(From: H.P. 113 - L.D. 155**  
**Resolve, To Establish the Commission To Study Difficult-to-place Patients**  
**Section 5 - Duties of the Commission)**

- 1. Identification of categories of patients with complex medical and mental health conditions who are unable to be discharged from hospitals because there are no facilities or providers who are able to care for them or to accept them for care;**

*As stated in our commentary (attached) it is our sincere hope that the Commission will recommend inclusion of neurodegenerative disease as a class addressed by this legislation. Not only for alternative housing options, but also recommending to DHHŠ that, for home care, neurodegenerative disease be included in the OTR (Other Related Conditions) category.*

- 2. A description of how patients with complex medical and mental health conditions are placed currently, including the involvement of staff from the Department of Health and Human Services;**

*As far as our research can tell, patients with neurodegenerative diseases, especially ALS, are not wanted by traditional nursing homes in Maine. Our foundation knows of one vented ALS patient, from Bangor, who was eventually placed in a home in Biddeford. We were told by that home's manager, that they wouldn't do it again. We were approached by a family who has a relative in a small, 8 bed nursing home Downeast, that the patient was asked to leave because "his care was too intense". Most important is the fact that the traditional nursing home is not equipped to provide quality care for an individual who remains cognitively aware but is completely, or partially paralyzed and perhaps vented. There is a specialized quality of care the traditional nursing home cannot provide profitably. That is why our plan includes partnering with a like-minded, mission driven non-profit, already operating along term care facility.*

- 3. Identification of primary barriers to placement of patients with complex medical and mental health conditions currently;**

*For neurodegenerative diseases, our take is that the most significant barrier is that these diseases are progressive by definition. Therefore, the care needs evolve over time, increasing in intensity of care. A patient may progress slowly, and have needs which remain stable for years. Conversely, a different patient may progress from needing a walker, to a wheelchair and being bedridden and totally paralyzed and ventilator dependent within 18 months.*

4. A description of facilities in which patients with complex medical and mental health conditions are currently placed, including whether the facilities are in-state and the costs associated with the patients' care;

*We are modeling our proposed residence after the 10 person Steve Saling ALS/MS Residence, housed in the 100 person Leonard Florence Center for Living in Chelsea, MA. The Leonard Florence Center is the nation's first urban Green House. The Green House model was developed by Dr. Bill Thomas and is the care model we plan to deploy in our residence. It was designed as an elder care model but has proven to be highly effective with the disabled population as well. We strongly encourage members of the Commission to tour the Leonard Florence Center and the Saling Residence. We would be happy to arrange a tour.*

5. Options for increasing availability of residential care and long-term care facilities, including conversion of existing facilities such as hospitals, nursing homes and the Dorothea Dix Psychiatric Center to long-term care facilities for specialized populations that are difficult to place for care, such as ventilator-dependent patients, geropsychiatric patients and bariatric patients;

*Again, specific to neurodegenerative disease, we feel strongly that, to effectively deploy the innovative care model required to best serve this population, new construction is required. The cost to retrofit an existing facility with the residential amenities which make this model work, would be cost prohibitive.*

6. Rates of reimbursement necessary to operate facilities to manage patients with complex medical conditions, including psychiatric conditions and neurodegenerative diseases;

*We do not have data for the state of Maine as of this time. We do have the following Medicaid numbers for the ALS/MS residence in Chelsea, MA:*

*The Medicaid rate for Leonard Florence Center:*

*Case-mix rate T:*

*MS and ALS (non-vented) - \$301.83*

*ALS Vent program - \$530.54*

7. Any other issue identified by the commission; and be it further



# THE HOPE-JG FOUNDATION

BECAUSE EVERY FAMILY WITH ALS MATTERS.

## FAQ's

### Who is John Gregoire and what is the Foundation all about?

John was in the early stages of launching his second consulting firm when he was diagnosed with ALS in December of 2007. He was given 18 months to live. Together with his wife Linda, the couple vowed to take on each challenge as their "new normal". Years later, after advocating for ALS and ALS research in Washington, DC and closer to home, the couple saw an unmet need for families living with the disease. They've connected with hundreds of families and have seen that technology, education (even within the medical community) and innovative care can make a tremendous difference in the quality of life of the afflicted and their families. Their recognition of the unmet needs of families with ALS led to the formation of The Hope-JG Foundation.

**The Hope-JG Foundation** is a 501(c)3 Non-Profit corporation dedicated to helping families living with ALS and other neuromuscular diseases, live life to its fullest by leveraging existing world class technology, supporting technical innovation and biomedical research. The foundation's initial, primary missions will be twofold:

- To establish a world class ALS/MS Residence in Maine similar to the first of its kind facility founded by Steve Saling and Barry Berman at the Leonard Florence Center for Living in Chelsea, MA.
- To inspire and promote innovative technologies which enrich the lives of families living with ALS and other neuromuscular diseases.

### What is ALS and how many people affected by this?

Amyotrophic lateral sclerosis (ALS), sometimes called Lou Gehrig's disease, is a rapidly progressive, invariably fatal neurological disease that attacks the nerve cells (neurons) responsible for controlling voluntary muscles (muscle action we are able to control, such as those in the arms, legs, and face). The disease belongs to a group of disorders known as motor neuron diseases, which are characterized by the gradual degeneration and death of motor neurons.

Based on U.S. population studies, a little over 5,600 people in the U.S. are diagnosed with ALS each year. (That's 15 new cases a day.) It is estimated that as many as 30,000 Americans have the disease at any given time. (Source: The ALS CARE Database)

### Where does my donation go?

Donations to The Hope-JG Foundation go to our mission of building an ALS/MS Residence in Maine as well as our ongoing support for innovative approaches to care of the afflicted and their families. Our staff, Board and Advisory Panel are an all volunteer force.





# THE HOPE-JG FOUNDATION

BECAUSE EVERY FAMILY WITH ALS MATTERS.

## OUR PLAN

- 1** Partner with a like minded Long Term Care provider in Maine to build a 10 bed/person ALS/MS Residence with additional respite space.
- 2** Together, develop a plan for renovation or construction with input from The Green House Project team.
- 3** Initiate a capital campaign and engage with philanthropic groups to cover construction and ongoing operational costs.
- 4** Begin construction.
- 5** Continue to identify and develop relationships with world class Innovators to enhance the lives of residents and other disabled individuals.
- 6** Support the residence thru ongoing fundraising, philanthropy and (hopefully) an operational presence at the residence.

*\*Our ultimate financial goal is to endow each of the 10 beds in the residence to secure long term viability.*





# THE HOPE-JG FOUNDATION

BECAUSE EVERY FAMILY WITH ALS MATTERS.

## THE GREEN HOUSE® PROJECT



### ALS/MS RESIDENCE

The vision for this specialized residence is based on the Green House® model, a unique concept intended to deinstitutionalize long-term care by eliminating large nursing facilities and creating a home within a community setting.

The ALS and MS Green House® residences are "smart" houses that promote and support independence, regardless of the stage and/or progress of illness. Due to the unique architecture, small footprint of each Green House, and innovative technology, wheelchair-bound individuals have independent mobility with meaningful choices and dignity.

### THE GREEN HOUSE® PROJECT

THE GREEN HOUSE® Project offers a model for long-term care designed to look and feel like a real home. Over the last decade Green House homes have set a new standard for quality care with a model that is both proven and practical.

Today there are hundreds of Green House homes open or in development in the majority of states. Our evidence-based model has been proven — through independent research — to be effective, feasible and sustainable. Our technical assistance is a big reason why The Green House Project has become a preferred partner in helping organizations meet demands of the changing long-term care market.

### WHAT CAN I DO?

We have need for committed people with experience or expertise in fund raising, video production, event planning, grant request writing, networking, accounting, graphic arts, copy editing, finance, media, public relations, healthcare regulations, long term care, technology or administrative support. If you have a heart for families fighting incurable disease... WE WANT TO HEAR FROM YOU!

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