Northern New England Collaboration: Clear as Mud

NPCR Directors’ Meeting
April 15, 2009

Molly Schwenn, ME
Bruce Riddle, NH
Ali Johnson, VT
Our talk will cover...

• Epi profile of the region
  – Bruce (NH)
• Tri-state collaboration & ME pilot study
  – Molly (ME)
• Access to care study
  – Ali (VT)
Northern New England
The New Hampshire House of Representatives is the largest state legislative body in the US with 400 members.
Northern New England Climate

Coldest

Maine -48\(^\circ\) on January 19, 1925
NH -47\(^\circ\) on January 29, 1934
Vermont -50\(^\circ\) on December 30, 1923
Northern New England Climate

_Hottest_

<table>
<thead>
<tr>
<th>State</th>
<th>Temperature</th>
<th>Date</th>
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<tbody>
<tr>
<td>Maine</td>
<td>105°</td>
<td>July 10, 1911</td>
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<tr>
<td>NH</td>
<td>106°</td>
<td>July 4, 1911</td>
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<tr>
<td>Vermont</td>
<td>106°</td>
<td>July 4, 1911</td>
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## 2008 Population Estimates

<table>
<thead>
<tr>
<th>State</th>
<th>Population</th>
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<tbody>
<tr>
<td>Maine</td>
<td>1,316,456</td>
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<tr>
<td>New Hampshire</td>
<td>1,315,809</td>
</tr>
<tr>
<td>Vermont</td>
<td>621,270</td>
</tr>
<tr>
<td><strong>Northeast</strong></td>
<td><strong>54,924,779</strong></td>
</tr>
<tr>
<td>United States</td>
<td>304,059,724</td>
</tr>
<tr>
<td><strong>Northern New England</strong></td>
<td><strong>3,253,535</strong></td>
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We are older and whiter.

<table>
<thead>
<tr>
<th></th>
<th>2005-2007 Median Age</th>
<th>Percent &gt; 65</th>
<th>Percent White</th>
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<tbody>
<tr>
<td>Maine</td>
<td>41.1</td>
<td>14.7</td>
<td>95.5</td>
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<tr>
<td>New Hampshire</td>
<td>39.3</td>
<td>12.4</td>
<td>95.0</td>
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<td>Vermont</td>
<td>40.4</td>
<td>13.3</td>
<td>96.2</td>
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<tr>
<td>Northeast</td>
<td>38.4</td>
<td>13.7</td>
<td>77.0</td>
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<tr>
<td>United States</td>
<td>36.4</td>
<td>12.5</td>
<td>74.1</td>
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# Female Cancer Rates, 1999-2004

<table>
<thead>
<tr>
<th></th>
<th>Count</th>
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<th>Age-Adjusted Rate</th>
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<tbody>
<tr>
<td>US</td>
<td>3,106,864</td>
<td>689,870,041</td>
<td>414.1</td>
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<tr>
<td>Maine</td>
<td>18,533</td>
<td>3,323,452</td>
<td>456.3</td>
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<tr>
<td>NH</td>
<td>15,671</td>
<td>3,227,856</td>
<td>445.3</td>
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<tr>
<td>Vermont</td>
<td>7,671</td>
<td>1,566,664</td>
<td>427.3</td>
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# Male Cancer Rates, 1999-2004

<table>
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<tr>
<td>US</td>
<td>3,341,918</td>
<td>667,446,122</td>
<td>561.0</td>
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<tr>
<td>Maine</td>
<td>20,419</td>
<td>3,160,503</td>
<td>621.9</td>
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<tr>
<td>New Hampshire</td>
<td>16,813</td>
<td>3,132,673</td>
<td>583.4</td>
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<tr>
<td>Vermont</td>
<td>8,381</td>
<td>1,512,696</td>
<td>567.3</td>
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</table>

fun fact

• It’s *not* true that largest industry in New Hampshire is the first-in-the-nation Presidential Primary.

• It’s *second*. 
Rankings

2005 Incidence, All Sites, Males:

#3 Maine
#6 New Hampshire
#30 Vermont
More Rankings

2005 Incidence, All Sites, Females:

#1 Maine
#3 New Hampshire
#9 Vermont
Yet More Rankings

2005 Mortality, All Sites, Males:

#10 Maine
#28 New Hampshire
#39 Vermont
Even More Rankings

2005 Mortality, All Sites, Females:

#5 Maine
#17 New Hampshire
#32 Vermont
New Hampshire’s Way

New Hampshire has no state income tax and no state sales tax but lots and lots of other taxes.
The Beginnings

Tri-State Conferences in Support of Registry Training

October 2002
December 2003
June 2007

Collaborative Stage
Advanced Abstracting
High Quality Training in Challenging Sites
New England Study of Environment and Health
a.k.a. New England Bladder Cancer Study

- First ME, NH, VT cancer registry collaboration
- Population-based case control study based at NCI
- Began 2000; accrual 2001 – 2004; analysis and writing underway
- Participants: ME, NH, and VT
  - Arsenic in ground water, 4+ in ME & NH (Also in RI, Eastern MA)
- Objective: Determine reason for high incidence & mortality of bladder cancer in northern New England (men and women)
New England Study of Environment and Health
a.k.a. New England Bladder Cancer Study

• Measurements
  – Residential, Occupational, Smoking & Diet Histories
  – Water testing (esp. private wells); toenail clippings, other samples
  – DNA (GWAS Studies at NIH)

• Eligible: 1213 cases and 1418 controls

• Findings: Too early to report (papers submitted)
Differences Among Northern New England States

- Rates and Rankings
- Products
- Recent Legislation
- Other Facts and Factoids
## 2008 Rates and Rankings

<table>
<thead>
<tr>
<th></th>
<th>ME</th>
<th>NH</th>
<th>VT</th>
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<tr>
<td>Smoking (%)</td>
<td>20.2</td>
<td>19.3</td>
<td>17.6</td>
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<tr>
<td>Air Pollution (mcg fine particles/m$^3$)</td>
<td>9.9</td>
<td>9.5</td>
<td>9.5</td>
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</table>
## Rates and Rankings

<table>
<thead>
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<th></th>
<th>ME</th>
<th>NH</th>
<th>VT</th>
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</thead>
</table>
| **Overall Health**
(rank; 2008)              | 9  | 3  | 1  |
| **Public Health Funding**
($ per person; 2008)      | 51 | 59 | 143|
Products

• Maple Syrup: VT #1; 460,000 gallons/yr
• Blueberries: ME #1; 90,000,000 lbs/yr
• Lobsters: ME #1; 72,000,000 lbs/yr
• And, of course, mud!
Recent Legislation

- Vermont legislature overrides gov’s veto of same-sex marriage law
- New Hampshire finally passes seat belt legislation (motto is “Live Free or Die!”)
- Maine legislature still debating motorcycle helmet law
Maine’s Treatment Studies

- Colon Cancer
- Breast Cancer
ME Colon Cancer Tx Study

• identified a significant opportunity for improvement in the management of patients:
  – evaluate nodal sampling in Stage IIB & III colon cancer
  – evaluate administration of adjuvant chemotherapy
Chemotherapy in Stage IIB Colon Cancer

• 50% of patients <12 nodes biopsied
• 38% of patients received adjuvant chemotherapy
• 58% of patients recommended to receive chemotherapy
Chemotherapy in Stage III Colon Cancer

- 31% of patients < 12 nodes biopsied
- 62% of patients received adjuvant chemotherapy
- 79% of patients were recommended to receive chemotherapy
ME Breast Cancer Tx Study

- identified areas for statewide improvement in breast cancer therapy:
  - sentinel lymph node (SLN) biopsy
  - post-lumpectomy radiation
SLN in Stage I and II Breast Cancer

Ideal Benchmark = 100%
Maine: Stage I = 60.6%
Stage II = 49.2%

Improvement over time: 11% increase over 3 years (2002 to 2004) in Stages I & II
Post-Lumpectomy Radiation Standards

• Benchmark
  – Stage 0 = 95%
  – Stage ≥ I = 100%

• Best Practice
  – Stage 0 = 91%
  – Stage I = 85%

• Maine
  – Stage 0 = 71% (for <70 yo)
  – Stage I = 83%
  – Stage II = 78%
Post-Lumpectomy Radiation by Region

Androscoggin
Kennebec
Aroostook
Washington
Cumberland
York
Sagadahoc
Lincoln
Somerset
Franklin
Oxford
Hancock
Piscataquis
Knox
Waldo
Penobscot

\[74.5\%\]

\[74.5\%\]

\[\blacktriangledown \blacktriangleup = \text{statistically significant}\]
Tri-State Collaboration

- Staging and Treatment Issues
- Colon and Breast
- 2003 and 2004 data
- Compares treatment in rural and urban areas (3 tiers in the 3 NNE states)
- Collaboration by conference call & email
Scope of the Project

- rural/urban access to care
- multi-state CCC partnerships
- multi-state CCR data collection
- maintain the important & tenuous infrastructure providing services to people in rural communities
NNECOS
Project Aims – Colon Cancer

1. Do patients in rural areas present with higher stage of cancer?

2. Is there a rural/urban difference in adjuvant chemo for Stage IIIB/III cancers?
Project Aims – Breast Cancer

1. Is there a rural/urban difference in sentinel lymph node dissection?

2. In the percentage of women who receive post-lumpectomy radiation therapy?
Deliverables

• Receive data from cancer registries.
• Organize and analyze data.
• Jointly publish a report.
• Distribute report to health planners and researchers.
• Disseminate data in journals and conferences.
Obstacles to Overcome

To paraphrase John L. Young, Jr., DrPH, CTR of the Rollins School of Public Health…

“You never know what you will find in your data until you actually start to use it.”
Obstacles

- Exchanging de-identified across state lines
- Minimum cell size issues even with 3 states but 2 years
- Different required data items
  - TNM not required in every state but needed to compare to clinical guidelines
- Changes in staging variables
  - 2003 to 2004
Best Stage

- Is the diagnosis year 2004?
  - Yes: Assign final stage group as Registry Derived TNM [3000]
  - No:
    - Is Registry path descriptor ['221Y' or 'M&Y'] known?
      - Yes: Assign final stage group as Registry cTNM [970]
      - No:
        - Is Registry pTNM stage group known? ([910] /= '9' or '8' or ' ')
          - Yes: Assign final stage group as Registry pTNM [910]
          - No:
            - Is Registry cTNM stage group known? ([970] /= '9' or '8' or ' ')
              - Yes: Assign final stage group as Registry cTNM [970]
              - No:
                - Is there sufficient text to assign stage?
                  - Yes: Assign final stage group based on text provided.
                  - No: Assign final stage group as unknown.
More Obstacles

– Following back to hospital registrars for “cleaner” data
– Non-hospitals/hospitals without cancer registrars
– Development of a common set of definition of analytic variables and common tables
– The common SAS program and consolidation of tables
Mechanics

- One SAS program run at three places
  - Not the same as running it in one place
- Different conceptions of what a “table” is
  - Column/row percent
  - Exclusions (unknown, n/a, etc.)
fun facts

- Montpelier, VT is the smallest state capital in the U.S. (Pop. < 9,000)
- It’s the only U.S. capital without a McDonald’s.
The Access to Care Project timeline

- MCC treatment WG studies: 2006-2007
- The early meetings: May – October 2007
- MCC data presented at tri-state mtg. and at NNECOS mtg.
- Project Team convened to apply for funding: October 2007
- NNECOS receives ASCO grant award: February 2008
- Project Team convened (but not complete): April 2008
- A little clearer that this is a CCR project
- Castine goes to work for NPCR
- First mtg. of 3 states' CCR's: May 2008
- Study parameters begin to be defined: July 2008
The Access to Care Project

timeline

- Project Team complete ~ kick-off meeting
- study timeline established
- Bruce writes first SAS code
- CRANE & NNECOS meetings
- follow-back method developed
- follow-back for stage and treatment
- rural/urban defined
- publication workgroup forms
- first data reviewed
- data analysis complete
- final report

- September 2008
- October 2008
- December 2008
- January 2009
- February 2009
- March 2009
- April 2009
fun fact

• Beetlejuice was partially filmed in VT.
If We Could Do It All Over Again
(a.k.a. Our Advice to You)

• Timeline
  – spread the work out over the project period
  – don’t wait until the last minute
  – plan on extra time for rerunning data
  – establish a cut off date for “final” analysis
Don’t procrastinate like we did.
If We Could Do It All Over Again
(a.k.a. Our Advice to You)

• Study Design & Analysis Plan
  – define as much as possible early in the process
  – establish the parameters of the follow-back process
  – clarify roles & responsibilities
  – detail the specifications
Qualities of Collaborative People

• tenacity
• experience
  – differences in state reporting
  – standards changes
  – clinical guidelines
  – statistical programming & analysis
  – program management
• motivation
• communication
• organization
• a good sense of humor
fun facts

• Ben & Jerry's gives their ice cream waste to local VT farmers use it to feed their hogs.

• The hogs seem to like all of the flavors except Mint Oreo.
Next Steps

– Cancer consortium planning and activities
– Update the data periodically
  • look for trends in access to quality care
– Consider other questions
– Future Northern New England collaborations with and outside NNECOS
– Evaluation of cost of TNM reporting -- related to V. 12 implementation?
Special Thanks

Dr. Lisa Rutstein, Maine Cancer Liaison Physician Chair
Office of Information Services, Maine Medical Center
Maine Cancer Consortium
 Maine Cancer Registry
 American Cancer Society
 Centers for Disease Control & Prevention
 American Society of Clinical Oncology
 Northern New England Clinical Oncology Society
# Project Team

## MAINE

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
</tr>
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<tbody>
<tr>
<td>Dan Hayes, MD</td>
<td>Maine Center for Cancer Medicine</td>
</tr>
<tr>
<td>Melanie Feinberg*</td>
<td>Maine Medical Center</td>
</tr>
<tr>
<td>Dawn A. Nicolaides, CTR*</td>
<td>Maine Cancer Registry</td>
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<tr>
<td>Molly Schwenn, MD*</td>
<td>Maine Cancer Registry</td>
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## NEW HAMPSHIRE

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
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<tbody>
<tr>
<td>Lori Aubrey*</td>
<td>Northern New England Clinical Oncology Society</td>
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<tr>
<td>Maria O. Celaya MPH, RHIT, CTR*</td>
<td>NH State Cancer Registry</td>
</tr>
<tr>
<td>Sai Cheralal*</td>
<td>NH DHHS and Office of Health Statistics and Data Management</td>
</tr>
<tr>
<td>Matthew Katz , MD*</td>
<td>Radiation Oncology Associates</td>
</tr>
<tr>
<td>Judith R. Rees, MPH, Ph.D.*</td>
<td>NH State Cancer Registry</td>
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<tr>
<td>Brian Strohm, Ph.D.</td>
<td>NCI/CIS Partnership Program</td>
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## VERMONT

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Deborah Dameron, MSPH</td>
<td>American Cancer Society</td>
</tr>
<tr>
<td>Terry Dawson, CTR</td>
<td>Vermont Cancer Registry</td>
</tr>
<tr>
<td>Ann Gray, CTR*</td>
<td>Fletcher Allen Health Care</td>
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<tr>
<td>Ted A. James, MD</td>
<td>University of Vermont</td>
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<tr>
<td>Ali Johnson, CTR*</td>
<td>Vermont Cancer Registry</td>
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<tr>
<td>Johannes C. Nunnink, MD*</td>
<td>Principal Investigator</td>
</tr>
<tr>
<td>John Olson</td>
<td>Comprehensive Cancer Control Program</td>
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<tr>
<td>Leigh Sampson</td>
<td>American Cancer Society</td>
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<tr>
<td>Christian Thomas, MD</td>
<td>VT Center for Cancer Medicine</td>
</tr>
<tr>
<td>H. James Wallace III, MD</td>
<td>Fletcher Allen Health Care</td>
</tr>
</tbody>
</table>

* Publications Committee Member


# State Organizations & Agencies

## MAINE
- ACOS Commission on Cancer, Cancer Liaison Program
- American Cancer Society
- Maine Bureau of Health
- Maine Cancer Consortium
- Maine Cancer Registry
- Maine CDC

## NEW HAMPSHIRE
- NCI/CIS Partnership Program
- New Hampshire Comprehensive Cancer Collaboration
- New Hampshire Department of Health and Human Services, Office of Health Statistics and Data Management
- New Hampshire State Cancer Registry

## VERMONT
- American Cancer Society
- Comprehensive Cancer Control Program
- Vermont Cancer Registry
- Vermont Department of Health
- Vermonters Taking Action Against Cancer
# Health Care Centers

## Maine

**Blue Hill Memorial Hospital**  
Blue Hill, ME 04614-0823

**Bridgton Hospital**  
Bridgton, ME 04009

**Calais Regional Hospital**  
Calais, ME 04619-1398

**Cary Medical Center**  
Caribou, ME 04736-2599

**Central Maine Medical Center**  
Lewiston, ME 04240-0305

**Coastal Cancer Treatment Center**  
Bath, ME 04530

**Down East Community Hospital**  
 Machias, ME 04654

**Eastern Maine Medical Center**  
 Bangor, ME 04401-6674

**Franklin Memorial Hospital**  
 Farmington, ME 04938-9990

**Henrietta D Goodall Hospital**  
 Sanford, ME 04073-2645

**Houlton Regional Hospital**  
 Houlton, ME 04730-9998

**Inland Hospital**  
 Waterville, ME 04901-4595

**Maine Coast Memorial Hospital**  
 Ellsworth, ME 04605-1599

**MaineGeneral Medical Center**  
 Augusta, ME 04330

**MaineGeneral Medical Ctr**  
 Waterville, ME 04901-4974

**Mercy Hospital of Portland**  
 Portland, ME 04101-3795

**Mid Coast Hospital**  
 Brunswick, ME 04011

**Miles Memorial Hospital**  
 Damariscotta, ME 04543-9767

**Millinocket Regional Hospital**  
 Millinocket, ME 04462-1298

**Mount Desert Island Hospital**  
 Bar Harbor, ME 04609-0008

**Northern Maine Medical Center**  
 Fort Kent, ME 04743-1497

**Parkview Adventist Medical Ctr**  
 Brunswick, ME 04011-3398

**Penobscot Bay Medical Center**  
 Rockport, ME 04856-4240

**Penobscot Valley Hospital**  
 Lincoln, ME 04457-0368

**Redington Fairview Gen Hosp**  
 Skowhegan, ME 04976

**Rumford Hospital**  
 Rumford, ME 04276-2145

**Scarborough Radiation Therapy Ctr**  
 Scarborough, ME 04074

**Sebasticook Valley Hospital**  
 Pittsfield, ME 04967-1199

**Southern Maine Medical Center**  
 Biddeford, ME 04005-9496

**St Andrews Hospital**  
 Boothbay Harbor, ME 04538-1732

**St Joseph Hospital**  
 Bangor, ME 04401-3897

**St Mary's Regional Med Center**  
 Lewiston, ME 04240

**Stephens Memorial Hospital**  
 Norway, ME 04268-1297

**The Aroostook Medical Center**  
 Presque Isle, ME 04769-3171

**Veterans Affairs Med Center**  
 Togus, ME 04330

**Waldo County General Hospital**  
 Belfast, ME 04915-6072

**York Hospital**  
 York, ME 03909-1099
# Health Care Centers

## New Hampshire

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>City, State</th>
<th>Zip Code</th>
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<tbody>
<tr>
<td>Alice Peck Day Mem Hospital</td>
<td>Lebanon, NH</td>
<td>03766-2650</td>
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<tr>
<td>Androscoggin Valley Hospital</td>
<td>Berlin, NH</td>
<td>03570-3531</td>
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<tr>
<td>Catholic Medical Center</td>
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<td>Concord Hospital</td>
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<td>Cottage Hospital</td>
<td>Woodsville, NH</td>
<td>03785-2001</td>
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<td>Dartmouth-Hitchcock Med Ctr</td>
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<td>Elliot Hospital</td>
<td>Manchester, NH</td>
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<td>Exeter Hospital</td>
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<td>Franklin Regional Hospital</td>
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<td>Frisbie Memorial Hospital</td>
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<td>Monadnock Community Hospital</td>
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<td>New London Hospital</td>
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<td>Parkland Medical Center</td>
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<td>St Joseph Hospital</td>
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<td>Upper Connecticut Vly Hospital</td>
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<td>VA Medical Center</td>
<td>Manchester, NH</td>
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<tr>
<td>Valley Regional Hospital</td>
<td>Claremont, NH</td>
<td>03743-2099</td>
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<tr>
<td>Weeks Medical Center</td>
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<tr>
<td>Wentworth-Douglass Hospital</td>
<td>Dover, NH</td>
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## Health Care Centers

### Vermont

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Address</th>
<th>Phone</th>
</tr>
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<tbody>
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