

HEALTH DECISIONS

MARCH 2008 A PUBLICATION OF THE VERMONT ETHICS NETWORK VOL. 14, NO.3

Medical and Legal Experts Lead Regional Conference on Patients Without Surrogates

What do “un-befriended elders” who need surgery, troubled Veterans who may be homeless and estranged from their families, emancipated minors who may be going through mental health crises and need urgent care at hospitals and mental health centers have in common? They are patients who have no Advance Directives and no logical or available surrogate to give consent to needed treatment on their behalf. Every hospital, clinic and community has encountered these needy citizens but few have developed procedures or protocols for medical treatment in emergency situations. Guardianship services, public and private, are ill equipped for emergency situations and many hospital policies are idiosyncratic, working well for some but difficult to apply to other situations. Problems in this area of medical care and treatment will only increase as the proportion of elders without family or caregivers increases, another generation of severely injured and unsupported veterans returns to the streets, and drugs and substance abuse cripples more of our young people. **The Patient Alone: Making Health Choices for Patients Without Surrogates – May 6-7 in Boston** at the John Hancock Hotel & Conference Center is a unique Memorial Conference sponsored by American Health Decisions in honor of one of its founders, Mary Strong, Director of the New Jersey Citizens Committee on Biomedical Ethics.

Among the key faculty are noted experts in their field: **Dan Brock, PhD**, Head of the Division of Medical Ethics at Harvard Medical School, **Lachlan Forrow, MD** of Beth Israel Deaconess Medical Center in Boston, and **Muriel Gillick, MD** of Harvard Vanguard Medical Services. To address the legal issues from the standpoint of the populations most affected are national legal experts **Charles Sabatino JD** and **Erica Wood, JD** of the American Bar Association Commission on Law & Aging, **Naomi Karp, JD**, of the AARP Public Policy Institute and **Robert Fleischner, JD** from the Center for Public Representation. They and other colleagues will be available in working sessions on both days. The three areas that will be covered are *1. State, Statutory and Regulatory Responses ... 2. Organizational/System Responses, and 3. Interpersonal and Bedside Issues*. This is indeed a rare opportunity within our region for clinicians, legal services staff, public guardians, health system administrators, social workers and health systems policy developers. It is hoped that systems change models will be developed and tested at the State level with ideas and suggestions that come from the working sessions.

To view the full Conference Agenda, and to Register go to the **American Health Decisions website: www.ahd.org** Also, please let John Campbell at VEN know if you plan to attend as VEN hopes to facilitate follow-up discussions and planning in Vermont following the conference.

VPQHC to Host One-Day End-of –Life Collaborative Info Meeting on April 4

The **Vermont Collaborative on End of Life Care** has grown out of the work done by VEN and multiple professionals and champions in the hospice and palliative care movement. An initiative of the Vermont Program for Quality in Health Care, the Collaborative seeks to improve the quality of end of life care for all Vermonters through accelerated learning, innovation and change. The Collaborative will focus on: pain and symptom management, advance care planning, family and meaningfulness, and continuity of care. The Collaborative, based on the **Institute for Health**

Care Improvement model, is a gathering of teams of healthcare professionals and community members committing to a 9-12 month period of rapid change to improve health care in their communities. Each team will test a series of small-scale changes in consultation with other teams and experts from around the state. VPQ has seen this succeed in the Chronic Care arena, and IHI has used this model for improving end of life care at the national level. An informational meeting will be held at the **Capital Plaza on Friday April 4, 2008 from 8:30-3:00**. Topics will include an introduction to quality improvement and change methodology, information about the national Collaborative, a presentation on how this work has been applied in a local community, along with information about Advance Directives. There will also be time for participants to begin working on changes they would like to make in their own practice setting.

We encourage any professionals working with end of life care, including those in hospitals, primary care settings, emergency medical services, and nursing homes, to attend this informational meeting. For more information please contact **Patty Launer, RN** at **802-229-2152**, or at pattyl@vpqhc.org.

VERMONT ADVANCE DIRECTIVE REGISTRY - First Year is Successful

As of the first year anniversary of the Vermont Advance Directive Registry (VADR) on February 1, 2008 there were 1526 registrants and the system appears to be running smoothly. VEN has assisted the Vermont Dept. of Health with a series of outreach workshops at local libraries, senior centers, churches and conferences and has distributed nearly all of the 10,000 brochures "Registering Your Advance Directive" that was designed and published by VEN in September. The new edition of **Taking Steps** (11th edition, January 2008) also has the "Registration Agreement" form as part of the Advance Directive forms insert. A goal of 5000 would not be unreasonable for the second anniversary. We hope to work with a UVM Medical Student intern in the coming year, exploring roving "volunteer" clinics on VADR and the new AD forms at local doctors offices in the Burlington area.

NEXT STEP for the REGISTRY? A number of people, including clinicians and social workers in the field, have suggested that it is time to add **DNR Orders** to the Registry along with Advance Directives. This makes a lot of sense. The Advance Directive Statute requires health care providers, including emergency medical personnel, to check the Registry for all incapacitated patients. The new Advance Directive form contains a section on wishes concerning CPR or withholding CPR. Medical DNR orders are covered in the statute and are clearly meant to be "portable" between settings. There are legitimate concerns that EMS personnel in the field cannot take valuable time away from rescue efforts to hunt for documents that may or may not be in the Registry. However, we are much more sophisticated in our service delivery and technology than we were just five or ten years ago. Perhaps it is time to have a dialogue on improving the responsiveness of Emergency Medical Services to clearly stated patient wishes that have been backed up by formally signed DNR Orders and valid ID forms. It is no longer a good excuse to say that "we did not know the patient's wishes" when valid DNR orders are available – easily available – through the Registry, as well as better lines of communication between caregivers and First Response Services at the community level. Isn't it time to add this component to the Registry as clearly envisioned by the legislature when it passed Act 55 three years ago? Share your thoughts on this one by emailing me at vtethicsnetwork@silicondairy.net -John Campbell, VEN Executive Director

"Futile Care" will be the subject of the 27th DHMC Educational Program April 14

The twenty-seventh semi-annual educational program of the **NH/VT Hospital Ethics Committee Network at Dartmouth Hitchcock** will explore the issues of “Futile Care” in a new interactive workshop style. Led by Marcia Bosek, RN, DNSc and Drs. Bob Orr and Bob Macauley, the session that begins with the noon luncheon in Auditorium F will explore standards and application of ethical principals to clinical situations where there may be conflict about proceeding with treatment. The **Rural Ethics Network** organized and led by VEN will meet as usual in the morning, starting at 10 AM to look at current issues affecting hospital ethics committees and ways to address their needs. A second **Clinical Ethics Case Analysis and Documentation** course is being planned for the Southern part of the state, probably in the Fall, following a very successful 17-hour course over three days led by **Dr. Robert Orr** at CVMC this winter, attended by over 20 participants from four hospitals. The course evaluations were uniformly very positive. VEN was in charge of setting up and coordinating this course for “REN” members. If you plan to attend the afternoon conference at DHMC, you can register at <http://ccehs.dartmouth-hitchcock.org> . If you also plan on attending the REN meeting, please email John Campbell at johnc@silicondairy.net. There is no charge for the morning session. The afternoon session, including lunch, is \$30.

REVIEWS: Two recent books of note.

Better: A Surgeon’s Notes on Performance, by Atul Gawande, MD, Henry Holt & Co., NY (Metropolitan Books – paperback edition), 2007, 273 pp. ISBN 978-0-312-42765-8. “Our decisions and omissions are moral in nature.” So says Dr. Gawande, a surgeon at Brigham and Women’s Hospital in Boston and a frequent contributor to *The New Yorker*. That does not mean that they are always right or that nobody gets hurt by them. This book is not only an enticing read about some of the more absorbing macro issues in health care – Drs involved in executions (and torture); grading of hospitals and physicians based upon their performance and patient mortality; the indefatigable “fighting” spirit of modern health practitioners to continue to pursue treatment and cure – but also the intensely personal issues, such as losing a patient and loved one and wondering about the additional suffering that was involved. Medicine is a risky business. Not just because of the high expectations and the consequences of failure as measured by malpractice suits, but because of the stress that it imposes on all who enter that realm. In an afterword about becoming a “positive deviant” or change agent in this realm, Dr. Gawande gives a wonderful 5-step prescription for those with the courage to try. I won’t spoil it by telling you what it is, but merely commend it as sage advice to the experienced doctor as well as the novice contemplating a career in medicine.

Swimming in a Sea of Death, A Son’s Memoir, by David Rieff, Simon and Shuster, NY, 2008, 180pp. ISBN 978-0-7432-9946-6 This important book was panned by both the *New York Times* and the *BostonGlobe* for precisely the reasons that I found it compelling and heart-wrenching; the size of both reviews, however, testify that even its detractors acknowledge it as an important book from its unique window on a son’s suffering through his mother’s long dying process. Author and cultural commentator Susan Sontag was first diagnosed with Cancer in the early 1970’s, fought through breast cancer with radical mastectomies and then ovarian cancer in the early 1990’s and in her most determined and losing battle, she succumbed to a rare and virulent form of leukemia in 2004. (Ironically, Ms Sontag is most remembered by many for her seminal study *Illness as Metaphor*.) She did not “go gentle into that good night.” And by her side was her journalist son, whose relationship was adoring but not “close” except as an enabler and “cheerleader” for the impossible dream of the final recovery. He chronicles the feelings of guilt and sadness that his role created for him. This book is important precisely because it did not have a happy ending ... and was not exclusively about the patient.

... and a third book with excellent practical advice for patients, caregivers and others who want to support their friends in health crisis situations: **After Shock: What to Do When the Doctor Gives You – or Someone You Love – a Devastating Diagnosis**, by Jessie Gruman, PhD, Walker & Co., New York, 2007, 276 pp., paperback. ISBN: 978-0-8027-1502-9.

VENnotes - Upcoming Events and Workshops

- March 12 - Advance Directive Workshop - S. Burlington Public Library, Dorset St., at Noon**, led by VEN Director, John Campbell.
- April 4 – End of Life Care Collaborative (VPQHC) Conference on Improving Care Through Teamwork at the Local Level – Capitol Plaza, Montpelier 9-3pm.**
For more information contact Patty Launer at pattyl@vpqhc.org
- April 8 – Vermont Geriatric Conference for Primary Care Practitioners** at the Sheraton Burlington Conference Center, co-sponsored by the Area Health Education Centers (AHEC) Network. Register: <http://cme.uvm.edu> .
- April 14 – DHMC semi-annual education program for the NH/VT Hospital Ethics Network**
Preceded by the Rural Ethics Network (VT) meeting at 10 AM. (see article).
- April 16 – AD Workshop at the Good Living Senior Center in St. Johnsbury –**
From 1 pm – 2:30, following the noon meal. To register, call Susan at (802) 748-8470.
- April 27 - AD Workshops in Guilford and Westminster –** sponsored by the Brattleboro Pastoral Counseling Center. Call VEN for more information.
- May 6-7 - The Patient Alone: Making Choices for Patients Without Surrogates -**
John Hancock Conference Center, Boston, Mass. For program and registration Information visit the American Health Decisions website: www.ahd.org
- May 17 - Health Fair at Grace Cottage Hospital in Townshend, Vermont**

**Vermont Ethics Network
64 Main Street, Room 25
Montpelier, VT 05602**

www.vtethicsnetwork.org