Mr. Chair and Members of the Committee,

My name is Twila Brase. I am president of the Citizens Council on Health Care. Our mission is to support patient and doctor freedom, medical innovation and the right to a confidential patient doctor relationship.

One need only look at the bill, SF 2866, as well as the 2010 Report to the State Legislature to understand how far this will take Minnesota from the right to not be a subject of government surveillance and intervention.

But first, before I get into the sections of the bill, let me share with you a few problems noted by a consultant more than two years after the 2005 trauma system bill was passed, and which are reported in the 2010 report. These problems are important because this legislation is seeking additional funding under a deficit.

The consultant noted the department’s lack of consistency in adhering to their own criteria for trauma center designation. The consultant also noted that the trauma center designation is voluntary, rather than based on need. So anyone that wants it can go after it.

Now, to the bill. I will note just two sections.

First, on page 2, line 4 and page 3, line 22, the Department continues to be exempt from rulemaking requirements, prohibiting the public from effectively opposing any and all Department rules that take on the force and effect of law without ever having been voted on by their elected representatives.

Second, on page 3, line 5, there will be established a new centralized trauma registry to take the place of three separate systems they have used to gather private data piecemeal on individuals. In the 2010 report, it is of interest that the Department claims legislative authority to collect this data, however, they provide not actual statutory citations.

However, from their December 2004 report—used to push for the 2005 special session passage of the trauma system law—and from the Recodification Table provided by the Department (p. 2 - top right corner) where they discuss collecting this data for 17 years, we assume that they are referring to the very controversial, 1992 “all-patient-data-is-government-data” law, 62J.301 and 62J.321 which specifically forbids patient consent for government access to every detail in every medical record. This We also understand from that table that they have been collecting data in the current trauma registry using the traumatic brain injury and spinal cord injury definition in the 2005 trauma registry law (144.607).

Notably, they now intend to repeal the brain and spinal injury limits for data collection in favor of a law that would allow every injury from every person to be reported to the government.
The definitions of “trauma” for the current registry in 144.607 (only brain and spinal cord injured) would be expanded in the new registry to include the following definition from 144.602, as referenced on page 3, line 7 of the bill (which is also included in my handout):

"Major trauma" means a sudden severe injury or damage to the body caused by an external force that results in potentially life-threatening injuries or that could result in the following disabilities:

(1) impairment of cognitive or mental abilities;
(2) impairment of physical functioning; or
(3) disturbance of behavioral or emotional functioning.

The Department could interpret these terms very broadly. There is nothing in the bill that would prohibit broad interpretation and corresponding data collection.

And not only will data on individuals be reported, but the government would be empowered to track every patient’s outcome indefinitely and to track all treatment decisions. Again, there is nothing to prohibit it. Phase three of the 2010 report, as you can see on your handout makes it clear that the plan is to track patients after the injury:

“This also includes integrating outcome data into the trauma registry for a complete record of injury care.”

The title of Phase Three also clarifies the intent to impose government-endorsed treatment guidelines on patients. Hospital will undoubtedly have to follow them to keep their trauma hospital designation status (and the federal funds attached to that status). And additionally, the intent is to use patients captured in the trauma registry for research. All without their consent.

NOTE: The 2010 report asks to add a part-time person for research.

Page 10 of the 2010 report also notes that the Department’s vision for the trauma system is full integration into the public health system, which this bill will do. Our organization does not believe that residents of Minnesota wants their medical records, their treatment regimes, and their physical and mental status to fully integrated with the state health department.

This bill extends and deepens the Department’s ongoing violation of constitutional rights, patient rights, and privacy rights.

Minnesota has an unfortunately long history of conducting surveillance on citizens without their consent, as our new information card, containing a partial list of Minnesota surveillance systems which include no consent, makes clear.

Such surveillance and medical interference activities must not be extended into new and centralized systems. Instead, they really must come to an end.

Thank you.  (HANDOUTS BELOW)
Minnesota Has You

Under Surveillance

Why isn’t your consent required?

Why does government own your private medical data?

Why can Minnesota conduct research on you without your consent?

Why are state electronic health databases being linked to create ‘child health profiles’?


<table>
<thead>
<tr>
<th>Type of Data Collected</th>
<th>Name of MN Dept. of Health (MDH) Surveillance System</th>
<th>Year began</th>
<th># of People in Database*</th>
<th>Is Name Included?</th>
<th>Is Individual’s Consent Required?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth, Death, Marriage, Adoption</td>
<td>Vital Statistics</td>
<td>1915</td>
<td>Unknown</td>
<td>Y</td>
<td>N</td>
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<tr>
<td>Birth Defects</td>
<td>MN Birth Defects Info. System</td>
<td>2005</td>
<td>1,632</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Cancer</td>
<td>MN Cancer Surveillance System</td>
<td>1988</td>
<td>&gt; 500,000</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Diabetes</td>
<td>MDP Diabetes Surveillance System</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Unknown</td>
<td>N</td>
</tr>
<tr>
<td>DNA</td>
<td>Newborn DNA Repository at MDH</td>
<td>7/1/1997</td>
<td>&gt; 819,282</td>
<td>Y</td>
<td>N - but genetic privacy law (13.386) not followed</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>HIV/AIDS Reporting System</td>
<td>1982</td>
<td>12,000</td>
<td>Y</td>
<td>N</td>
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<tr>
<td>Genetic Test Results</td>
<td>MN Newborn Screening “Genetic Registry”</td>
<td>7/1/1986</td>
<td>&gt; 1.5 million</td>
<td>Y</td>
<td>N</td>
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<tr>
<td>Sexually Transmitted Diseases</td>
<td>STD Infonet</td>
<td>1994</td>
<td>120,247</td>
<td>Y</td>
<td>N</td>
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<tr>
<td>Strokes</td>
<td>MN Stroke Registry</td>
<td>2008</td>
<td>Unknown</td>
<td>Y</td>
<td>N</td>
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<td>Trauma Registry</td>
<td>MN Trauma Registry</td>
<td>2006</td>
<td>3,903</td>
<td>Y</td>
<td>N</td>
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<tr>
<td>Vaccinations</td>
<td>MN Immunization Info. Connection</td>
<td>2002</td>
<td>3.8 million</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

*Numbers low. Data was collected from MDH between 6/25/2007 and 1/12/2009. MDH collection of private data is ongoing and not limited to above systems.

CONTACT THE GOVERNOR & YOUR LEGISLATORS! Support our efforts to continue to inform the public! DONATE TO CCHC: www.cchconline.org
"Major trauma" means a sudden severe injury or damage to the body caused by an external force that results in potentially life-threatening injuries or that could result in the following disabilities:

1. Impairment of cognitive or mental abilities;
2. Impairment of physical functioning; or
3. Disturbance of behavioral or emotional functioning.

PHASE 3 (2010 Trauma System Report to MN Legislature)

**Phase 3**: Saving lives through full system integration, outcome-based clinical guidelines, and contribution to evidence-based bodies of literature

Rehabilitation of severely injured patients is a core component of the trauma system’s continuum of care. Building the system from the front end (i.e., EMS and the acute care phase of hospital evaluation, transfer and admission) has been the early focus of system development. But it is understood that integrating rehabilitation into the system is critical to ensuring that all Minnesotans are receiving optimal care for their life- and limb-threatening injuries. This is a challenging but key goal of Phase 3 system development.

This will require a review of related literature and identifying rehabilitation resources (especially for specialty populations and conditions such as pediatric, burn, spinal cord, brain injury), and develop a work plan to integrate rehabilitation into the system. *This also includes integrating outcome data into the trauma registry for a complete record of injury care.*

Although many injured patients attain their post-injury recovery goals fairly soon, others require prolonged in-hospital care and post-hospital rehabilitative services. The ultimate outcome is to return patients to their pre-injury state. A coordinated, multidisciplinary approach to early rehabilitative care produces the most favorable outcomes: restoring pre-injury physical status or to an optimal level of functioning. (p. 7)

Appendix C (2010 Report)
Hiring of a part-time research analyst is planned. [this added here since 3/3/2010 distributed handout]