

FAIR Fighting to Protect Consumers

Newsletter of Families Advocating Injury Reduction
Winter 2002

2001 A Year of Challenges, Transition for FAIR

Dear Members,

This past year dedicated FAIR members worked hard to effect changes within the IL Department of Professional Regulation (DPR). The most important bill introduced in 2001 was the Patient Right-to-Know Act, sponsored by Rep. Mary Flowers. Despite the tremendous support of Rep. Flowers, this bill once again failed to pass out of committee (see inside story).

Rep. Flowers also introduced HB 2158, which would require all physicians to carry liability insurance. This bill failed in committee but will be reviewed again this year.

HB 2163, sponsored by Reps. Saviano, Hamos, and E. Lyons, would have given the public members of the medical disciplinary board voting rights. With this bill's failure in committee, Illinois remains the only state whose public members can't vote on disciplinary matters.

All of these bills would have helped prevent countless deaths and injuries and would have put the rights of patients on par with those of physicians. Although we

lost on many key issues, FAIR members did not give up, standing their ground with a volunteer army and little money.

FAIR also influenced the Governor's decision to create a task force on patient safety. Although the task force did not include a consumer representative, FAIR actively participated in the hearings. Members Geri Schryver, Susan Bucher, and Sonia Rhodes provided powerful testimony on Patient Right-to-Know and holding health care providers accountable for their actions. These small victories should pave the way for major changes.

Since becoming a member of FAIR in 1994, I have seen incredible changes in the arena of victims' rights. Yet at times, the process has been too slow and painful. Many FAIR members succumbed to their injuries and died last year, including Curtis Bloome, Marla

Sebben, Thomas Jankowski, Marie Lundquist and Michael Welsh, to name a few. These extraordinary people testified, spoke at press conferences, and called their legislators because they believed in FAIR's mission. They'll be greatly missed.

December 2000 ended my two years of work as a staff person for FAIR. Last year Ruth Wyman and I continued to help FAIR as volunteers through the legislative session. Because of the lack of funds, the Coalition for Consumer Rights will now provide part time staff support for FAIR through its new Policy Director, Kristin Houlé. Although I'll stay involved as a member, working full time at another job will reduce the numbers of hours I can devote to FAIR. Yet like so many of you, my injury has impacted my life so profoundly that I will never give up and go away.

—Arlene Salamendra

Public Hearing on Patient Right-to Know

Mark your calendars!!! Representative Mary Flowers will sponsor a public hearing on Patient Right-to-Know in downtown Chicago during the last week in February.

All FAIR members interested in testifying should contact Kristin Houlé at the Coalition for Consumer Rights: (312) 939-4566 or KristinHouleCCR@aol.com.

More details will be forthcoming.

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FAIR 2001

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Thank you to all present and past members of our board.

Who We Are, What We Do

Families Advocating Injury Reduction (FAIR) is a statewide organization dedicated to protecting the rights of consumers and workers. Our members include injured consumers and workers and their families. Specifically, we seek to organize and empower injury victims and their families through:

Advocacy and Public Policy. In addition to opposing limitations on the legal rights of victims, FAIR is committed to developing and building public support for policies that promote safer consumer products, safety in the workplace, and better quality healthcare.

Public Education. Determined to counteract the onslaught of misinformation about injury victims and to educate the general public, the media, and policy makers, FAIR produces educational materials, sponsors a Speakers' Bureau, and organizes special events to highlight our concerns.

Leadership Training. FAIR works to empower consumers and workers by providing them with the necessary skills and information needed to effectively advocate and articulate their perspectives.

The defeat of Patient Right-to-Know legislation in the Health Care Availability and Access Committee has become an all-too-familiar refrain. Unfortunately, we did not witness a departure from this pattern in 2001. Despite the valiant efforts of FAIR members and the first-time support of such organizations as the Illinois Nurses Association, House Bill 246 did not clear the committee.

Sponsoring Rep. Mary Flowers (Chicago) and Reps. Soto (Chicago) and Kenner (Chicago) voted 'yes.' Reps. Krause (Mt. Prospect), Mulligan (Des Plaines), Miller (Dolton), Coulson (Glenview), and Ryan Jr. (Lansing) voted 'no,' and Rep. Klingler

(Springfield) voted 'present.' Reps. May (Deerfield) and Ryder (Jerseyville) did not attend the committee vote. The measure failed even after one major category of information – lawsuit settlements – was excluded from information DPR would be required to disclose about physicians.

HB 246 was defeated in a midnight committee vote on April 5, the day before the release of new national data condemning DPR. An analysis of data from the Federation of State Medical Boards conducted by Public Citizen ranked the Department of Professional Regulation in Illinois 44th in the nation in terms of medical enforcement. Nancy Cowles, former Executive Director of the Coalition for Consumer Rights, noted, "DPR seems

most committed to protecting its right to do nothing. Meanwhile, patients have no information to help choose a physician and no recourse if they are harmed."

While this latest legislative defeat may be discouraging, it in no way undermines FAIR's determination to keep fighting the good fight for patients' rights. Rep. Flowers plans to reintroduce the Patient Right-to-Know Act in the 2002 winter legislative session. She will also sponsor a public hearing on this legislation in downtown Chicago during the last week in February. We will send more details as soon as they become available. Please call Kristin Houlé at CCR, (312) 939-4566, if you are willing to testify at the hearing.

Coalition for Consumer Rights Releases 12th Annual Survey of Illinois Voters

Public Support for Medical Oversight Proposals Stronger Than Ever

In Fall 2001 the Coalition for Consumer Rights released its 12th Annual Survey of Illinois Voters. The survey included standard questions about medical malpractice insurance and Patient Right-to-Know, as well as a new question about medical error reporting. Results from the survey reveal that voter support for medical oversight proposals is stronger than ever.

- ◆ Over 88% of voters support giving consumers background information about doctors. This is a substantial increase over the 79% favoring Patient Right-to-Know in 2000.
- ◆ Ninety-two percent of voters agree that doctors should be required to have malpractice insurance.
- ◆ Nearly 97% believe that hospitals should be required to inform patients about medical errors.

Despite widespread public support for these proposals, the Illinois General Assembly has failed year after year to take decisive legislative action to protect patients from bad doctors. FAIR and its allies must continue efforts to channel public opinion toward pressuring legislators to support these vital oversight measures.

Renewed Emphasis on Patient Safety for the Joint Commission on Accreditation of Healthcare Organizations

Increase in "Wrong-Site Surgeries"

On December 5, 2001 the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) issued an alert warning of an alarming increase in the number of operations on the wrong body part or, even more horrifying, on the wrong patient. Since its last report on "wrong-site surgery" in 1998, the commission has uncovered 136 more cases – 11 in one month alone. Seventy-six percent of these cases involved operating on the wrong body part, such as the wrong knee, while 13% involved surgery on the wrong patient and 11% involved the wrong surgical procedure. If these figures weren't appalling enough, data collected by other agencies imply that healthcare organizations significantly underreport these kinds of surgical errors to the Joint Commission.

According to the commission, most incidents

occur when there has been a breakdown in communication between the surgical team and the patient and his or her family. As one preventative measure, JCAHO recommends patients and surgeons mark the appropriate body part with an 'X' to ensure the correct surgical outcome.

The commission plans to join forces with the American College of Surgeons and the American Medical Association to increase surveillance of surgical errors. Healthcare organizations that are not in compliance with patient safety procedures could risk losing their accreditation.

New Patient Safety Standards

The recent alert on "wrong-site surgeries" falls in line with the Joint Commission's renewed emphasis on patient safety. On July 1, 2001 new standards went into effect requiring hospitals to initiate specific efforts to

prevent medical errors and to tell patients if they have been harmed while receiving treatment. The standards specifically state:

"Patients and, when appropriate, their families are informed about the outcomes of care, including unanticipated outcomes.

"The responsible licensed independent practitioner or his or her designee clearly explains the outcome of any treatments or procedures to the patient and, when appropriate, the family, whenever those outcomes differ significantly from the anticipated outcomes."

(Revisions to Joint Commission Standards in Support of Patient Safety and Medical/Health Care Error Reduction; Standard R.I.1.2.2)

It remains to be seen how such reporting will be monitored and what impact these new standards will have on reducing medical errors in hospitals.

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FAIR Member Appointed to National Advisory Council

In 2001, the National Patient Safety Foundation (NPSF) established a Patient and Family Advisory Council. Long-time FAIR member and former staff person Arlene Salamendra was asked to serve on the council, along with eight other consumer representatives from across

the country. The council also includes eight NPSF Board members. Although the exact charge of the Advisory Council has yet to be determined fully, members have already met several times and have begun work on ensuring that hospital publications, such as informational

brochures, are understood easily by patients. Arlene noted that "through sharing the consumer perspective, we hope to provide useful information on how healthcare organizations and doctors can best communicate with patients." Congratulations, Arlene!

Efforts to Improve Children's Product Safety Receive Boost from Courts, Congresswoman

Legislation Would Require Safety Testing

On November 14, 2001 U.S. Rep. Jan Schakowsky (D-IL) introduced H.R. 3283, the Infant and Toddler Durable Product Safety Act. This legislation would require manufacturers to test children's products before selling them. According to the Consumer Product Safety Commission (CPSC), an average of 87 children under age 5 die each year in incidents associated with nursery products; over one third of these deaths were due to dangerous cribs.

If passed, H.R. 3283 would require the CPSC to establish a review panel to set safety standards for all durable and infant toddler products by December 31, 2005. An independent third party would

certify that the manufacturers' product has met these safety standards. Manufacturers could not release products that fail to meet the standards. The review panel would place a safety seal of approval on products.

Please urge your Members of Congress to support H.R. 3283.


Founders of Kids In Danger Settle Lawsuit; Resist Pressure for Secrecy

Such safety standards for children's products might have saved the life of Daniel Keysar, a 16-month-old who died when the top rails of his Playskool Travel-Lite portable crib collapsed, strangling him. The crib had been recalled five years earlier. Danny's parents, Linda Ginzel and Boaz Keysar, founded the

organization Kids In Danger to help prevent future deaths and injuries to children from unsafe products. On December 6, 2001 they reached a \$3 million settlement agreement in their case against manufacturers Kolcraft and Hasbro, one of the largest settlements on record for the death of a child from an unsafe children's product.

Despite the secrecy requests of the manufacturers, the final agreement stipulates that information about the dangerous crib product must be kept open and available to the public. This represents a unique victory for consumers, since Sunshine in Litigation laws that would ensure such openness have consistently failed to move through the Illinois General Assembly.

Ginzel and Keysar have pledged to use some of the settlement funds to continue the work of Kids In Danger, as part of Danny's legacy.



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