

### **PERSONAL HEALTH DECISION-MAKING**

Following the principles that individuals should be responsible for their personal health and should participate with their family and their physicians in decisions regarding it, the League has supported the following legislation:

- In 1989 with extensive League support, a law was passed concerning “do-not-resuscitate” instructions in hospitals and nursing homes. This law was expanded in 1991 to include home and ambulance sites.
- In 1989, the League supported legislation that establishes “living wills.” These instructions relieve family and health care providers of uncertainty should decisions need to be made when a patient is unconscious or incompetent.
- In 1990, the League supported health care proxy legislation, which became law in 1990 and took effect in January 1991. A proxy provides for alternative individuals to make health care decisions on the patient’s behalf.
- In 1995, the League supported the “Family Health Care Decisions Act”, which would allow family members of patients who do not have either a living will or a health care proxy to make decisions affecting their loved ones within specific guidelines.

The Task Force on Life and Law, appointed and funded by former Governor Cuomo in 1985, consisted of prominent physicians, nurses, lawyers, clergy of different faiths and others. The Task Force debated legal and ethical issues in medicine and developed the above referenced legislation. In the 1995-96 Executive budget the Task Force was defunded; it is still in existence with limited funding through the Department of Health.

Family Health Care Decision legislation continued to bubble under the surface through every legislative session. The League will continue to look for opportunities to advance this important legislation.

In the 2006 and 2007 legislation session the Family Health Care Decision, legislation was again introduced in the Assembly. However, major opposition to this legislation by the NYS Catholic Conference, the Conservative Party and the Right to Life Committee continue to hold sway in the NYS Senate. No action was taken.

### **HIV/AIDS**

In 1994, legislation was introduced by Assemblywoman Mayersohn and Senator Velella, which would unblind the newborn sero-prevalence test for HIV. Although unblinding would indicate the possible HIV status of newborns, it would disclose the absolute HIV status of the mother. The League opposed this legislation on the basis that it violates the right of individuals to make their own health care decisions. More importantly, we believed such a punitive measure would have a negative impact on promising new treatment programs that were reducing the rate of HIV transmission from infected mothers to their newborns. Therefore, the League actively supported legislation in the Senate that would mandate prenatal HIV counseling and voluntary HIV testing. This legislation did not pass in either house of the legislature.

In 1995 League wrote in support of a program, recommended by the Centers for Disease Control and implemented by the NYS Department of Health, that combined counseling and voluntary HIV testing with an aggressive AZT treatment program for HIV infected pregnant women. Once again, legislation opposed by the League and many health care providers and women's groups was introduced by Assemblywoman Mayersohn and Senator Velella to unblind the newborn HIV test. This bill passed in the Senate but was held by Assembly Speaker Silver.

In 1996, the Assembly Health Committee was pressured by the Assembly leadership to release the Mayersohn HIV Newborn Screening bill from Committee. This bill would give the Commissioner of Health authority to disclose the results of the newborn HIV test whether or not permission was given by the mother. Once out of Committee, this mandatory HIV testing bill passed both houses and was signed into law. In restating our opposition to the legislation and its implementing regulations, League argued (unsuccessfully) that the voluntary program already in place was working and that the prenatal HIV transmission rate was decreasing as predicted.

In 1998, League actively supported HIV name reporting/partner notification legislation. League recognized that the voluntary system of partner notification was not working. Notification had long played a role in controlling syphilis and gonorrhea and we agreed that HIV/AIDS should not be exempt from this life-saving practice. Primary prevention was paramount. The final version of the bill created a name-based surveillance system and a universal partner notification system. It gave public health workers primary responsibility for notifying the partners of HIV positive individuals. The legislation included safeguards that were essential for League support. These included: voluntary compliance; no criminal penalties for noncompliance; continuous anonymous testing option; creating protocols in cases of domestic violence; and, confidentiality of HIV individuals during the notification process. The legislation was passed by the legislature and signed into law by Governor Pataki.