



NORD ON-LINE BULLETIN

PEOPLE ARE TALKING ABOUT.....

"In my opinion it is very important to have people involved in decision-making who treat patients with that condition, because if you only look at risk, we wouldn't have any drugs. It wouldn't be sensible to have any drugs because they can all cause harm."
FDA official, Janet Woodcock, M.D., explaining why drug safety officials should work at FDA, and not at an independent agency.

"Safety has been trumped."
FDA safety officer David Graham talking about the recommendations of an FDA advisory committee to allow Cox-2 inhibitor drugs to remain on the U.S. market.

"Retiree healthcare coverage is kind of a slowly vanishing species."
Drew Altman, President & CEO of the Kaiser Family Foundation.

"Those of us who told you it was going to cost twice as much were right."
Representative Rahm Emanuel (D-IL) talking about new projections showing that the Medicare prescription drug benefit will cost \$720 billion over the next 10 years.

"When you put the fox in charge of the hen house, there is a problem."
JAMA editor Catherine DeAngelis reacting to the pharmaceutical industry's announcement that companies will "voluntarily" post clinical trial results on a Website.

"Medicaid is not meeting its potential. It is rigidly inflexible and inefficient. And worst of all, it is not financially sustainable."
New HHS Secretary Mike Leavitt talking about the need to change the Medicaid program, which serves the neediest Americans.

"Failing to address the healthcare crisis would be the worst kind of procrastination."
General Motors CEO Richard Wagoner concerned that American automakers cannot compete in the global market because of high health care costs in the USA.

"Never trust a computer you can't throw out a window."
Computer guru Steve Wozniak



"Every aggrieved party in any similar litigation now will go to Congress and ask us to make a series of decisions."

Rep. Barney Frank (D-MA) talking about emergency legislation to prolong the life Terri Schiavo, a Florida woman in a persistent vegetative state, whose case has been debated in Florida courts for many years. The new law allowed federal courts to overturn the decisions of Florida courts.

"Unfortunately, the votes of the (FDA) Advisory Committee are now, justly or unjustly, tainted."

Senator Chuck Grassley (R-IA) expressing his concern that the FDA did not reveal potential conflicts-of-interest for members of an FDA Advisory Committee that recommended Cox-2 inhibitor drugs could remain on the market.

"People are feeling tired and frustrated and don't know where we're headed."

A Centers for Disease Control (CDC) administrator talking about internal dissention at CDC.

"What they are saying to states is, 'We're going to cut your funding and give you more flexibility', and the flexibility is you can cut people off (Medicaid)."

Governor Jim Doyle of Wisconsin, talking about the President's proposals to restructure Medicaid.

"We hope physicians all over the country will rise up in opposition to what Congress has done."

Internist George Susens, who opposes Congress' passage of legislation regarding the Terri Schiavo feeding tube case, raising questions about families' future ability to make decisions to deny or discontinue life support of a loved one.

NEW HHS SECRETARY

President Bush nominated, and the Senate has confirmed Michael O. Leavitt as the new Secretary of Health and Human Services (HHS). Mr. Leavitt is the former Governor of Utah, and former Administrator of the Environmental Protection Agency (EPA).

"Medicaid (the government health insurance program for people living poverty) is flawed and inefficient," said Mr. Leavitt at his confirmation hearing. He said that state officials need more freedom and flexibility to reshape their Medicaid programs, trim benefits, and expand or cut back eligibility.

The Secretary also told the Senate Health Committee that FDA, CDC, and NIH are three of his departments "brands" that have "earned the public's

trust. If they lost their reputations, they would take years to recover." Some Senators, however, talked about FDA's recent drug safety problems and the erosion of public trust in the agency. Leavitt disagreed with that perception.

Subsequent to the nomination hearings, the President's budget projected \$60 billion in cuts over the next 10 years for the Medicaid program, and redirecting that money to other health-related programs such as tax credits for the purchase of health insurance. The Census bureau, however, says that since 2000 the number of uninsured Americans has risen by 5.2 million people.



FEDERAL BUDGET

Medicaid Victory Not Final

Thanks to the activism of many organizations who were concerned that proposed budget cuts to Medicaid would leave our neediest citizens without medical care, the U.S. Senate approved an amendment restoring \$14 billion for Medicaid funding to the Senates FY06 budget resolution. The amendment also created a federal commission to study and make recommendations about possible changes to the Medicaid program in the future.

The vote for the amendment was 52 to 48. All Democrats voted for it along with the following Republicans: Gordon Smith (OR), Lincoln Chafee (RI), Norm Coleman (MN), Susan Collins (ME), Mike DeWine (OH), Olympia Snow (ME), and Arlen Specter (PA). (* See related story: Terri Schiavo and Medicaid)

President's Bush's proposed budget had called for \$60 billion in Medicaid reductions over the next 10 years. However, Governors from both parties strongly objected to these proposed cuts.

Unfortunately, the House of Representatives voted 218-214 to approve a different budget resolution that calls for steep cuts in Medicaid and other entitlement programs. The resolution calls for \$69 billion in cuts to Medicaid and Medicare over five years, which is \$18 billion more than President Bush had proposed.

Now the House and Senate budget committees have to merge their resolutions and derive compromise legislation. The White House released a statement favoring the House Budget Resolution. Both the House and Senate proposals call for extending current tax cuts and adding even more.

Other Budget Cuts

The President's proposed budget eliminates 14 Health and Human Services programs, saving \$970 million, including emergency medical services for children, hospital construction, traumatic brain injury programs, and hearing tests for infants.

Other budget cuts the White House called for are: \$1.2 billion from vocational education; \$437 million from the safe and drug-free schools program; and \$496 million in education technology grants to schools. The Centers for Disease Control (CDC) would receive a six percent budget cut, while FDA would receive a modest increase of 4.4 percent. The Veterans Administration (VA) would get a one percent increase, and veterans using VA medical services would have to pay a \$250 annual fee plus co-pays. The President initially proposed a tiny \$196 million increase for NIH, but the Senate budget resolution calls for a more substantial increase of \$1.5 billion.

NIH RESTRUCTURING

The House of Representatives has decided that the NIH should be restructured. Congress last reauthorized the NIH in 1993. The Chairman of the House Energy and Commerce Committee, Joe Barton (R-TX), says that NIH should "streamline" its "topsy-turvy" management.

NIH was composed of seven institutes in 1960, and it is a conglomeration of 27 institutes today. It has more than 60 research programs that are funded through 26 separate line items in the federal budget. However, many of the new institutes and programs were created because Congress directed the agency to do so.

NIH Director, Elias Zerhouni, has created an Office of Portfolio Analysis and Strategic Initiatives, which is supposed to coordinate research efforts between institutes. Critics fear that efforts to restructure the NIH may get bogged down in political wrangling about embryonic stem cell research and other bioethical controversies. Additionally, constituent groups will probably oppose merging of institutes



that are responsible for studying their disease. Some are predicting that it will be much harder to merge institutes together than it was to create them.

NIH Ethics Rules Tightened

In response to recent research controversies, Dr. Elias Zerhouni has imposed "drastic" restrictions on stock ownership and other forms of outside income for NIH employees. In recent months, Congress identified several high profile cases of conflicts-of-interest that were not revealed by NIH researchers. NIH employees are required to report outside income, but many have not done so.

NIH employees have complained that Dr. Zerhouni's proposal punishes all of NIH's 18,000 employees for the unethical conduct of a few scientists. When Dr. Zerhouni tried to defend the employees at congressional hearings, he was embarrassed to learn that more than 100 scientists had not disclosed receipt of money from pharmaceutical and biotechnology companies, even though they are required to do so by government rules. Investigations later reduced the number of scientists who had these secret deals.

The NIH Director said he had no choice but to put draconian measures in place even though it may restrict NIH's ability to attract and retain scientific talent. Dr. Zerhouni says the goal is to restore public trust in the federal scientific enterprise after embarrassing revelations about corporate money given to NIH employees studying issues that may affect those companies. In one case, for example, Pfizer allegedly paid an NIH researcher a half million dollars over five years, and the salaried researcher did not report the income as required by NIH ethics rules.

being a victim of a terrorist attack. Nearly 47 percent in one survey said they are very worried about having to pay more for their health insurance. Another survey asked about the most important health problem that the government should address; 46 percent said healthcare costs, 25 percent said access to health care, and 16 percent said senior citizen health issues.

The federal government says that healthcare inflation is slowing. In 2003, it increased 7.7 percent compared to 9.3 percent in 2002. But for the first time in history, healthcare spending in the USA **exceeded 15 percent of the gross domestic product** (\$1.7 trillion, amounting to 15.3 percent of GDP). Insurance premiums increased 9.3 percent in 2003, compared to 10.6 percent in 2002, and out-of-pocket healthcare spending increased by 7.6 percent in 2003 as more costs were shifted to employees. Prescription drugs account for 23 percent of out-of-pocket healthcare spending.

The government says:

- Healthcare spending in 2003 averaged \$5,670 per U.S. resident.
- Private healthcare spending increased by 8.6 percent in 2003.
- Private health insurance enrollment decreased by one percent in 2003, and healthcare spending outpaced average wage growth of 2.9 percent.
- Medicaid spending (for needy people) accounted for 16 percent of total American healthcare spending in 2003.
- Total spending on Medicare (for the elderly and disabled) increased by 5.7 percent.
- Hospital care accounted for almost one-third of total U.S. healthcare spending.

States

HEALTHCARE COSTS

Kaiser Family Foundation surveys indicate that the American public is very concerned about healthcare inflation. One survey showed that Americans are more worried about their healthcare costs than about losing their job, paying their rent or mortgage, or

Governors are complaining about healthcare inflation, and in particular the escalating costs of Medicaid. The National Governor's Association says Medicaid costs in 2004 for the first time **exceeded the costs of elementary and secondary education** in their states. Additionally, state government employees receive health insurance from their



employer, the state. Therefore, high healthcare inflation impacts states on several levels.

Congress said the states would save 10 percent of drug costs due to the clawback provision.

Medicaid is partially paid by state governments and partially by the federal government. These costs are expected to increase 12.1 percent this year.

Unfortunately, states are quite concerned that they will lose millions of dollars for several reasons:

Retirees

Retirees who receive health benefits from their former employers saw their health care costs increase 25 percent this year, according to the Kaiser Family Foundation. Seventy-nine percent of employers said they increased premiums for retirees this year, and 45 percent said they increased co-pays. The proportion of large companies offering retiree health benefits fell from two-thirds in 1988 to one-third in 2004. Many people who wanted to retire early report they are staying at their jobs to age 65 in order to be eligible for Medicare before they lose their employer's insurance.

- ✓ Clawback payments will be based on state Medicaid expenses in 2003, and many states have been able to reduce their Medicaid drug expenses since 2003.
- ✓ States have been negotiating prices with drug manufacturers, achieving deep discounts. However, the new Medicare law prohibits Medicare from negotiating prices, so the federal government will not be getting drugs as inexpensively as state Medicaid programs. State Medicaid programs have also used preferred drug lists, rebates, and a limit on the number of monthly prescriptions. So the 90 percent payment based on 2003 drug expenses will not accurately reflect current spending levels.
- ✓ Congress added a clawback payment inflation factor that will increase the funds that states have to send to the federal government each year.

**DUAL ELIGIBLE
MEDICARE/MEDICAID**

In January 2006, when the new Medicare prescription drug benefit goes into effect, people who are eligible for both Medicare and Medicaid will henceforth be receiving their prescription drug benefits from Medicare. Until now, only Medicaid has paid for prescription drugs. Congress intended that the new Medicare benefit would reduce state government's costs for drugs, but it may actually cost the states more than they are paying now.

Some state government officials have questioned the constitutionality of the new law because it requires states to subsidize a federal program. One official from the Council of State Governments said, "This is a sea-change in the state-federal relationship. Money generally flows down from Washington to the states, but in this case it's flowing upward from the states to the federal government."

Under the current system, state and federal governments share Medicaid costs. When Congress developed the *Medicare Modernization Act*, they shifted much of the prescription drug costs for needy beneficiaries from Medicaid to Medicare, which is paid solely by the federal government. In an effort to get some of the money back; however, they included a "clawback provision," which requires states to pay back to the federal government 90 percent of the prescription drug costs of dual eligible people.

MEDICARE

RX Test Application

The Center for Medicare and Medicaid Services (CMS) is testing an application for financial assistance to needy people who cannot afford the new Prescription Drug benefit. 2,050 randomly selected Medicare beneficiaries will be sent the application. If they do not mail it back within two



weeks, they will be contacted by phone to find out why.

Beneficiaries with annual income at or below 150 percent of the federal poverty level (and assets that do not exceed a certain level) may qualify for a full or partial discount on premiums, deductibles and other fees. CMS is mailing the application early to a test sample so they can identify potential problems with the application. However, CMS is unlikely to have enough time to correct problems because the application is due to be mailed to all Medicare beneficiaries this summer.

Unfortunately, **the application is 16 pages long.** Additionally many Medicare beneficiaries complain the new program is too confusing to understand. Many advocacy groups have already asked CMS to simplify the application because it is too long and intimidating. For example, it contains a warning that people who provide false information “may be sent to prison or may face other penalties, or both.” However, CMS has not altered the application.

If your agency represents a substantial number of Medicare beneficiaries, they may need help filling out the application. You may want to have volunteers available to help fill out the forms and to interpret the questions. The forms can be found on the CMS.gov Website, along with instructions.

RX Drug Discount Cards

Many low-income Medicare beneficiaries can qualify for a \$600 subsidy through the prescription drug discount card program, but they have not applied for it. The government estimates that seven million Medicare beneficiaries probably qualify for the subsidy, but only 1.73 million have enrolled so far.

If a beneficiary enrolls before March 31, 2005 they will receive the full \$600 subsidy this year. If they enroll after that date, they will receive a subsidy ranging from \$150 to \$450, depending on when they enroll.

RX Program Cost

When Congress passed the Medicare Modernization Act, they were told the new program would cost no more than \$400 billion over 10 years. However, at the beginning of March 2005 the Congressional Budget Office (CBO) said the prescription drug benefit will actually cost \$849 billion over 10 years, which is more than twice what it was supposed to cost. In January, CBO had projected the new law would cost \$795 billion, and on February 8, 2005 CBO said it would cost \$720 billion. Last December the Bush administration said the cost would be \$534 billion. All of these estimates are guesses, and much depends on how many beneficiaries actually sign up for the new coverage.

Some conservative deficit hawks in Congress would like the law to be repealed, but the President says he will veto any attempt to change or roll back the law. Some liberals in Congress complain that the costs keep going up and up, but the scope of the inadequate benefit stays the same. The U.S. comptroller General said the new drug benefit “is one of the largest unfunded liabilities ever undertaken by the federal government,” and he warns it may cripple our economy.

Medicare Regulations

The final regulations for implementing the Medicare prescription drug benefit have been published by CMS. To read a summary of the regulations, go to the Website of the Kaiser Family Foundation (www.KFF.org) and click on Medicare.

Medicare Help-Line

Medicare’s toll-free telephone line (1-800-Medicare) was investigated by the Government Accountability Office (GAO) to see if it gives accurate answers to callers. GAO found that people got accurate answers some of the time: Twenty-nine percent of callers received inaccurate answers, and 10 percent got no answers at all. When doctors called the help-line they received accurate answers to their billing questions only four percent of the time, 54 percent of the answers were wrong, and 42 percent were incomplete or only partly correct.



A CMS contractor operates the help-line. It received 16.5 million calls in the fiscal year ending September 30, 2004. As a result of this GAO investigation, the help-line staff was re-trained. Beneficiaries can also get answers on the CMS Website, but less than one-third of people age 65 or over have ever gone on the Internet.

Medicare Drug Price Negotiations

Under the Medicare Modernization Act, Congress prohibited Medicare from negotiating with pharmaceutical companies to reduce drug prices. Some in Congress felt this was one reason that the new RX benefit will cost so much.

On March 17, 2005 Senators Olympia Snowe (R-ME) and Ron Wyden (D-OR) tried to pass an amendment giving the Department of Health and Human Services (HHS) the power to negotiate Medicare's prices with drug manufacturers directly. The law was defeated 50 to 49. Wyden said that failure to enact cost-containment measures for the new law would put the prescription drug benefit in jeopardy as costs spiral out of control in the future.

**SOCIAL SECURITY V S. MEDICARE:
Which Is In Worse Shape?**

The **Social Security and Medicare Board of Trustees** released their annual report on March 23, 2005. Three cabinet secretaries then held a news conference emphasizing the funding problems of Social Security saying, "It's on an unsustainable course." However, the report says that Medicare's funding problems are far worse than the retirement fund, and Trustees who felt the emphasis should be on fixing Medicare were not invited to the news conference.

Social Security benefits are scheduled to exceed tax revenues by 2017. Medicare, however, started paying out more for medical bills of beneficiaries last year than is paid in by taxpayers each year. The Social Security Trust Fund will be exhausted by

2041, but Medicare's Trust Fund will be depleted in 2020 (which is only 15 years from now).

A consumer trustee said, "The problem is they've got the cart before the horse. They've made Medicare vastly worse," referring to the Bush administration, "adding a prescription drug benefit last year, and now they're saying to be responsible, we have to take on Social Security. It's utterly illogical."

Medicare's total unfunded liability is \$65.4 trillion, which is almost six times Social Security's unfunded liability. The new Medicare prescription drug benefit has exacerbated Medicare's financial predicament because Medicare taxes are not sufficient to pay for it. Despite these dire warnings neither Congress nor the President have put Medicare's plight on their priority list. President Bush has pledged to veto any attempt to change the new prescription drug benefit or to raise taxes.

NEW FDA LEADER IS NOMINATED

President Bush has nominated Dr. Lester Crawford for the post of FDA Commissioner. Dr. Crawford has been the Acting Commissioner since last March when Commissioner Mark McClellan left the agency to become the chief of the Centers for Medicare and Medicaid Services (CMS). Dr. Crawford also served as Acting Commissioner from President Bush's first term in office until Dr. McClellan was nominated.

Dr. Crawford is a 66-year old veterinarian who also has a degree in pharmacology. He has worked at the FDA on and off since 1978. He is known as an expert on foods and veterinary medicine.

Pharmaceutical industry trade groups applauded the nomination, but some consumer groups and others expressed disappointment. Dr. Jerome Avorn, a Harvard Professor of Medicine said, "This is disappointing news because it was on Dr. Crawford's watch that many of the worst recent crises in drug safety have occurred." The Executive Director of the Center for Science in the Public Interest, Dr. Michael



Jacobson said, "He's not my ideal candidate, but the devil you know is better than the one you don't."

Nevertheless, fans and opponents of Dr. Crawford agree that the FDA needs a permanent leader as quickly as possible because public confidence in the FDA has been shaken, and internal reforms are needed at the agency.

FDA Budget

Despite numerous crises at the FDA, President Bush has proposed only a 4.4 percent budget increase for 2006. This will force the agency to cut back on inspections of food and drug manufacturers, such as the British factory that made flu vaccine. The budget calls for a \$6.5 million increase for the Office of Drug Safety so it can add 25 more workers.

If the President's budget is accepted, inspections of foreign drug manufacturers will be cut 5.8 percent, food inspections will decrease 5 percent, and blood bank inspections will be cut 4.7 percent. At a time when safety of the food and drug supply is of paramount importance to the public, those cuts will likely make public health more vulnerable to improperly manufactured products and bioterrorism.

FDA Testimony

On March 1, 2005 NORD's President, Abbey Meyers, testified before the Senate Health, Education, Labor, and Pensions Committee about the need for FDA reform. To read her testimony, go to NORD's Website: www.rarediseases.org. Under the article entitled "Does the FDA Need Reform?" click on: (read the text of her remarks).

Terri Schiavo and Medicaid

In 1993 Michael Schiavo won \$750,000 in a medical malpractice judgment for the brain damage suffered by his wife. The money was put in a trust fund administered by an independent trustee for the care of Michael's wife, Terri Schiavo. Terri was in a persistent vegetative state for many years. The money was spent on her care in nursing homes and a hospice that cost \$80,000 per year.

Michael wanted to disconnect the feeding tubes that kept Terri alive, but her parents objected. As the House and Senate debated a federal law to enable Terri's parents to appeal to a federal court, feeding tube, they also debated deep and painful cuts to the FY2006 federal budget for Medicaid.

In 2005 Florida will be spending about \$14 billion on Medicaid. The state covers 41 percent of Medicaid costs and the federal government pays the remainder. For every \$1 that Florida taxpayers spend on Medicaid, it receives \$1.44 from the federal government in matching funds.

Just before Congress voted to enable Terri Schiavo's parents to appeal to federal courts so the feeding tube could be reinserted, the U.S. House of Representatives voted to slash the FY2006 Medicaid budget by \$15 to \$20 billion over the next five years. But when Senate budget leaders proposed to cut \$14 billion from Medicaid, 52 Senators objected: All Democrats plus seven Republicans.

Medicaid is the federal healthcare program for needy disabled people that pays for nursing home care. Reductions in funding would have a drastic effect on the most fragile sector of our society: The elderly and severely disabled people who cannot live independently.

In 1999, when George Bush was Governor of Texas, he signed a law establishing procedures for hospitals and physicians to withhold life-sustaining care from people with hopeless medical conditions, even if their relatives protested. Families in Texas are given 10 days notice to find another facility if they disagree. The motivation for that law was obviously to save Medicaid money.

The Schiavo case illustrates that the same politicians who forced legislation through Congress to extend the life of one Medicaid patient, can vote to destroy this critically important healthcare program by starving it of money to operate. The federal law was literally signed by President Bush in the middle of the night, and lawyers immediately appealed to the



federal courts. However, the husband prevailed and this Medicaid patient, Terri Schiavo, was finally allowed to die.

RESEARCH

Some Plants Can Fix Their Genes

Geneticists at Perdue University have found that some plants can replace their defective genes, as if they have back-up copies from former generations that can bypass the usual mechanisms of heredity.

The discovery has been described as “really strange and unexpected.” It defies Mendel’s laws of inheritance. Evolutionary biologists have long believed that genetic mutations have led to the evolution of different species. If plants and animals can correct their own mutations, it poses problems for evolutionary theory.

Scientists were studying a mustard-like plant called arabidopsis with a mutated gene that made the plants’ petals clump together. The plants had two copies of the mutated gene so they had no chance of having normal offspring. However, ten percent of the plants’ offspring kept reverting to normal. When the scientists analyzed the mutated genes in the offspring, they found they had changed back to normal genes.

Much more research is needed to understand why this happened and whether it could occur in other plants and animals. Understanding how genes can be changed will hopefully lead to human medical applications.

Scientists Alarmed About Bioterrorism Research

Seven-hundred and fifty-eight scientists who have received grants from NIH, or have served on committees that award NIH grants, have sent a petition to NIH Director Elias Zerhouni expressing their concerns that tens of millions of research dollars are being shifted to bioterrorism research.

They feel this has reduced funding on other bacteria and viruses that cause major public health problems. The scientists say the bioterrorism research is on diseases that do not occur in the USA or are non-existent such as smallpox or anthrax.

Since 2001, the petition says funding for anthrax research has increased fifteen fold, while grants for communicable diseases such as tuberculosis and syphilis have decreased between 27 percent and 41 percent. A Rutgers University scientist said, “The diversion of research funds from projects of high public health importance, to projects of high biodefense but low public health importance, represents a misdirection of NIH priorities.”

Gene Therapy Hits Another Snag

A third child treated in France for X-Linked Severe Combined Immune Deficiency (SCID) with gene therapy has come down with cancer as a result of the gene transfer. Additionally, a monkey who was treated with gene therapy six years ago in an American laboratory has died from cancer.

The French SCID gene therapy trial was considered an absolute success because some of the children were apparently cured of SCID. However, several years later one child has died from cancer and two others diagnosed with cancer are undergoing chemotherapy. The cancer that appeared in the monkey six years after the gene therapy indicates that long-term as well as short-term risks may discourage future research on this technology. Scientists believe that the virus that ferried the gene into cells caused the cancer.

Chicken Pox and Shingles

In 1995, Merck started selling a vaccine against chickenpox. Since then, the U.S. mortality rate from the virus has fallen to 66 cases. There are still 800,000 cases of chicken pox annually in the U.S. because only 85 percent of American children are vaccinated.



However, the death rate from the virus for adults over the age of 50 has not fallen, and scientists feel it may be because of an increase in cases of shingles. The same virus causes both diseases. In childhood it appears as chicken pox, and in adults it appears as shingles when the long-dormant chicken pox virus is reactivated in adults.

Researchers say when adults are exposed to children with chicken pox, it acts like a booster shot to the adult's immune system. However, because of the chicken pox vaccine, few adults are currently being exposed to the virus. The immunity they may have had as children (after they recovered from childhood chicken pox) does not apparently last throughout life, and it can reoccur as shingles.

British infectious disease experts say that cases of shingles in adults may increase 30 percent to 50 percent because the chicken pox vaccine has been so successful in wiping out the disease. Since shingles can cause serious and painful complications in adults, some scientists suggest that children should not be vaccinated and others feel that older adults should be vaccinated, to prevent occurrence of shingles.

Obesity Studies Fabricated

A leading obesity researcher has admitted to fabricating data in 17 applications for federal research grants. Dr. Eric Poehlman acknowledged fabricating results from 1992 to 2002 including several published studies about the effects of menopause on weight.

Under a plea agreement with federal prosecutors, Poehlman will be barred for life from receiving federal research funds, he will reimburse the government \$180,000, he will plead guilty to criminal charges of fraud, and he will retract and correct 10 of his journal articles that were published about obesity and menopause.

Another Difference Between Men and Women

The Human Genome Project has announced that men and women can differ genetically by as much as two percent. There is only a one percent genetic difference between humans and chimpanzees.

The researchers completed mapping of 1,098 genes on the female X chromosome. Women have two X chromosomes and men have an X and a Y chromosome. They learned that as many as 300 genes on the female chromosome are activated differently than they are in men. They also identified 43 additional genes on the female X chromosome that can cause conditions such as cleft palate, blindness, and testicular cancer.

Whooping Cough Boosters

Since the 1940s, children have been vaccinated against whooping cough. However, scientists have recently realized that the vaccine wears off over time, and a booster shot may be needed. In 2004, Centers for Disease Control (CDC) received 18,957 reports of whooping cough compared to 11,647 in 2003 and 1,707 in 1980. In April or May of this year, FDA is expected to announce approvals for two new booster shots against whooping cough.

Technology Transfer: The Pros and Cons

In 1980, Congress passed the Bayh-Dole Act, which encouraged universities to patent discoveries and inventions that evolved from federally-funded research. In the late 1970s, universities filed about 250 patents per year. In 2003, they filed 3,500 patents.

The goal of Bayh-Dole was to encourage transfer of technology to the commercial sector. Before the law was enacted, universities released their discoveries to the public through academic publications such as medial journals. Today they delay publication until a patent is filed, and anyone who subsequently uses



the information for a commercial product must pay a licensing fee to the patent holder.

Some experts suggest this may hinder the progress of scientific research, and universities are no longer acting as neutral scientific institutions. For example, universities are more likely to encourage research on genetically modified crops, but scientists studying the environmental effects of biotechnology-engineered agriculture are "starved of resources."

Dr. Marcia Angell, former editor of the New England Journal of Medicine asked, "Is academic medicine for sale?" Her answer was "No, the current owner is very happy with it."

MEDICAL BANKRUPTCY

Each year about two million Americans file for bankruptcy because of health-related costs. A study by Harvard researchers published in the journal Health Affairs, says that 46.2 percent of bankruptcies in 2001 cited illness and medical bills as the cause. Seventy-six percent of these people had health insurance when they became ill, and 38 percent lost their health insurance at least temporarily by the time they declared bankruptcy.

Now Congress has changed the bankruptcy law and made it more difficult for Americans to win relief from bankruptcy judges because of medical bills. The legislation imposes a "means test" that gives judges less discretion to distinguish between people who abuse the bankruptcy system by simply spending too much, and those who deserve protection because of medical bills. Those with annual incomes that exceed the median income in their state will be required to follow a repayment plan.

Democrats introduced several amendments to the bankruptcy bill that would have expanded protections for people driven to bankruptcy due to medical bills, and for people called up to military service. The Senate rejected all of the democratic amendments.

MALPRACTICE

President Bush has made malpractice insurance reform a top priority, but Congress has not passed it. The House of Representatives have passed the legislation seven times, but each time it was stopped in the Senate.

Several studies have shown that malpractice costs are less than two percent of overall healthcare spending. If the cost of malpractice insurance was lowered by 30 percent, it would lower healthcare costs by only 0.5 percent. Thirty-four states have enacted caps on malpractice awards, but malpractice insurance costs have not been lowered significantly.

Some experts say that the problem is the insurance industry, not the judicial system. The Harvard School of Public Health says fewer than one in 15 out of 750,000 patients who are injured in hospitals each year file lawsuits. Of those who sue, only about 25 percent receive money. Many lawyers refuse to take cases if they will not be lucrative. Other healthcare providers remain silent about mistakes.

FEDERAL ABSTINENCE PROGRAMS

The curricula of more than a dozen federally-funded abstinence programs, aimed at preventing teen pregnancy and sexually transmitted diseases, is "false misleading, or distorted information" according to congressional investigators. The programs have taught teenagers during the past three years that abortion can lead to sterility and suicide, half of the gay male teenagers in the United States have tested positive for the HIV virus, and that touching a person's genitals "can result in pregnancy."

This year alone Congress will provide \$170 million to groups that teach "abstinence-only" to children between 9 and 18 years of age.

Other misinformation taught by the groups include: The HIV virus can be spread via sweat and tears; a 43-day old fetus is a "thinking person;" and condoms



fail to prevent transmission of HIV up to 31 percent of the time.

ANOTHER CANADIAN MAD COW

Another case of Mad Cow Disease has been identified in Western Canada (Alberta). Until a few weeks ago, the cases involved older cattle that were born before feed restrictions were instituted in 1997. The latest infected cow, however, was born after 1997.

The Bush administration recently repealed its ban on importation of Canadian cattle. As of March 7, 2005, Canadian beef can be sold to Americans if the cows are less than 30 months old. A group of Montana ranches, however, have sued to stop importation of Canadian livestock saying the meat would endanger public health, as well as the health of other cattle.

The outbreak of Mad Cow Disease in Canada has cost the Canadian cattle industry \$4 billion and 6,000 jobs. When the first case was discovered in 2003, many countries closed their markets to Canadian beef. The fact that the latest Canadian cow identified with the disease was born after the feed ban was in place may indicate that the feed ban was not effectively enforced. Montana ranchers say that 59 percent of Canadian feed that they tested contained "unidentified animal protein" even though such protein is banned as an additive to animal food.

Connection to Drug Importation?

Canadian officials have confirmed that when President Bush met with Prime Minister Paul Martin on November 30, 2004 they discussed reimportation of prescription drugs from Canadian mail-order pharmacies along with the Canadian cattle ban. A few weeks later, the Canadian government started cracking down on the Canadian pharmacies, and discussing a law that would prohibit Canadian doctors from re-writing prescriptions for patients who live outside Canada.

A spokesperson for the Canadian International Pharmacy Association, which represents 35 Canadian mail-order pharmacies aid that Canada's Health Department was very supportive of the four-year old mail-order industry until President Bush visited Ottawa. The spokesperson went on to suggest that President Bush demanded that cross-border prescription drug sales must end, possibly in exchange for the USA lifting the ban on Canadian beef imports.

Spokespersons for President Bush and Prime Minister Martin deny that any deal was made. But in early 2005 the Bush administration announced they would lift the ban on Canadian beef.

GENETIC NON-DISCRIMINATION

The Genetic Information Non-Discrimination Act (S.306) passed the U.S. Senate on February 17, 2005 with a vote of 98-0. Unfortunately, even though the bill has passed the Senate several years in a row, the House of Representatives has refused to bring it up for a vote.

The law would prevent insurance companies and employers from denying health coverage or job opportunities on the basis of genetic information. This year Representative Judy Biggert (R-IL) has introduced a companion bill in the House of Representatives (H.R. 1227). It is hoped that this year congressional leaders will allow a vote on the bill in the House of Representatives.

NEWBORN SCREENING

An advisory panel for the Department of Health and Human Services (HHS) has recommended that newborns be tested for a minimum of 29 heritable diseases nationally. The report was issued on March 8, 2005 in the Federal Register: "Newborn Screening: *Toward a Uniform Screening Panel System.*"



Right now some states screen for as few as three diseases and some screen for more than 40. The three basic diseases are phenylketonuria (PKD), medium-chain-acyl-CoA dehydrogenase deficiency, and congenital hypothyroidism. The Committee said that only 32 states currently mandate screening for more than 30 diseases. Nine states require screening for five disorders or less.

New high-powered screening technologies will allow faster screening for more disorders. The Committee suggests that several states could use one screening machine rather than each state having to purchase the technology.

MOVING ON

Former Secretary of Veterans Affairs, Anthony Principi, announced he will be Pfizer's new Vice President of Government Relations.

Former HHS Secretary, Tommy Thompson, has announced he has accepted a position as partner at the Washington, DC law and lobbying firm of Akin, Gump, Strauss, Hauer & Field. He will also be a senior advisor at the accounting and consulting firm of Deloitte & Touche. Thompson will also serve as President of Logistics Health, a firm that focuses on medical issues for the military.

When Thompson resigned his cabinet position in December 2004, he said he wanted to go home to Wisconsin and spend more time with his grandchildren.

PAIN GUIDELINES

Many doctors who treat pain are becoming more fearful that they can be arrested for practicing good pain control. Pain control specialists had negotiated a compassionate policy that was put on the Drug Enforcement Administration's (DEA) Website last year, but DEA suddenly took it off their Website in October 2004. On November 16, 2004 DEA issued new guidelines that were considerably tougher. It allows DEA to investigate doctors merely on suspicion that a law is being violated, or even if DEA

simply wants assurances that laws are not being violated. DEA will consider the number of tablets they receive and the length of treatment. All of these things "may indeed be indicative of diversion" their guidelines say.

Pain specialists are very concerned that the new guidelines may discourage doctors from prescribing proper pain medicines to patients. "We're seeing more of an emphasis on law enforcement and less on the legitimate use of prescription narcotics," said one pain specialist. "The tone of the dialogue has changed in a way that is very worrisome."

CHILDHOOD VACCINES

The federal government has maintained a childhood vaccine fund to ensure that low-income children (who do not qualify for Medicaid) will receive the vaccines that they need. However, last year when it became evident that we would have a shortage of flu vaccine, the government needed money to buy flu vaccine from foreign sources. So they took the money from the childhood vaccine fund.

State public health officials and medical associations complained that it was wrong to protect adults at the expense of children. The childhood vaccine fund is called the 317 program, and it provides \$220 million in federal funds to prevent serious diseases in needy children whose parents cannot pay for the injections. Finances of the fund have declined in recent years as the cost of vaccines has risen, and as new vaccines have been added to the standard regimen. Five years ago the program immunized 750,000 children, but this year it will reach only 467,000.

The CDC says the money was the most readily available when the flu vaccine shortage occurred, and the government hopes to reimburse the program for childhood immunizations. So far, 19 states have decided not to provide all of the recommended vaccines to children who qualify for the program.

MALPRACTICE INSURANCE RIGGED



New York Attorney General Elliot Spitzer and Connecticut Attorney Richard Blumenthal have launched an investigation into whether insurance companies have improperly raised the cost of malpractice insurance for doctors and lawyers. The costs of these policies have dramatically increased in recent years, or the insurers refused to renew policies for no apparent reason.

Blumenthal says the "excessive rates result from anti-competitive or illegal behavior" by insurance companies. Mr. Spitzer is probing the entire insurance industry since last October. He says that evidence suggests the entire field of professional insurance is suffering from big rigging and kickbacks. Some insurers are settling out of court. Insurance companies, however, say that there is a "litigation explosion," and that is the reason that insurance premiums are raising.

YOUR MEDICAL INFORMATION BUREAU (MIB) RECORD

If during the past seven years you have applied for life, health, or disability insurance, it is likely that your health record is on the Website of the Medical Information Bureau (MIB). MIB is an association of insurance companies that tracks medical records. When you sign a form allowing an insurance company to check your medical records, it is likely that they will check your records on MIB.

Now the Fair and Accurate Credit Transaction Act, which gives us free credit reports, will also give us access to our own health report once each year at MIB. If the information is not accurate, let them know.

You can reach MIB at: <www.mib.com>. Go to "consumer site." Click on "Request your record" or you can phone MIB at: (866) 692-6901.

FOREIGN NURSES

Updating of security measures has led the U.S. State Department to suspend the issue of temporary work

permits for foreign workers. This will especially affect the shortage of nurses in the USA because thousands of nurses have been imported from the Philippines for the last several years.

Foreign nurses used to obtain American work permits within 60 days. In the future it is expected to take up to three years to obtain these permits. Experts predict the USA may have a shortage of 275,000 nurses by 2010.

INFANT MORTALITY INCREASES

"The average baby is less likely to survive in the U.S. than in Beijing or Havana," said *New York Times* columnist Nicholas Kristof when the Centers for Disease Control (CDC) issued its report about the infant mortality rate. The United States ranks 42nd on the list of nations. Singapore has the best infant mortality rate in the world.

The infant mortality rate in the U.S. increased in 2002 for the first time since 1958. Seven infants die out of every 1,000 births. More American women are giving birth to low-birth weight babies who die before age one according to CDC; 41 percent of all infant deaths in 2002 were low-birth weight babies. Race, advanced maternal age, and multiple births were not related to the higher mortality rate.

RARE DISEASES ARE EXPENSIVE

Several states have special programs that cover the medical costs of serious diseases that start in childhood. The programs were generally begun because of a 1935 law for children afflicted with polio and other serious diseases. Now they tend to cover diseases such as cystic fibrosis, spina bifida, hemophilia, cerebral palsy, etc. Because the cost of treating rare diseases has risen greatly, many states such as Ohio, Idaho, Virginia, and Minnesota are considering eliminating or reducing these programs.

One reasons the cost of these programs is rising, is the success of modern medical treatments. The



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programs were supposed to cover incurable illnesses, but today the children are living longer with diseases that used to be fatal. For example, children with cystic fibrosis used to die in childhood. By the 1980s incremental treatment advances allowed them to live into their teenage years. Today the median life expectancy of a person with cystic fibrosis is 33 years. However, some of their medications can cost as much as \$2,000 per dose, and treatments for other genetic diseases such as enzyme deficiencies can cost more than one hundred thousand dollars per year (e.g., hemophilia, Gaucher's disease, fabry's diseases, etc.).

State governments say they cannot afford to pay these huge costs for diseases that are no longer fatal. Maternal and child health programs are not growing in proportion to the costs and the federal government is reducing its contribution to the programs. Some states are shifting the children to Medicaid requiring parents to "spend down" to poverty), others are charging higher, out-of-pocket costs for families, and others are eliminating benefits for those who have reached adulthood.

Ohio had a \$19 million program covering 21,000 children and adults with 80 diseases, most of which were rare. But one uninsured child with a heart defect can cost \$1 million per year. The budget was cut 12 percent last year, and another 5 percent cut is scheduled for this year.

## A WORD ABOUT CHARITIES

American charities are having a tough time, not because a slow economy has diminished donations from the American public, but because epic tragedies have drawn the public's attention and donations away from non-profit agencies that have traditionally benefited from the public's generosity.

The September 11 calamity raised record high donations four years ago as Americans rushed to help surviving families. As a result, in 2001 many traditional charities were unable to meet their budgets. The following years indicated a slow economic recovery due to the recession, which

meant that families didn't have extra money to donate to charities. In 2004, traditional charities had to compete with political fundraising campaigns. Then at the end of 2004, the tsunamis occurred and again Americans showed their heartfelt compassion for the millions of people who suffered in that epic human tragedy.

Unfortunately, however, American charities that often rely on end-of-year gifts from generous donors, struggled at the end of 2004. Donations were not good for all except the international aid organizations.

The *Chronicle of Philanthropy* says, "The bleak outlook for 2005 comes after a year in which many charities struggled to raise enough money to keep pace with inflation, which was 3.3 percent in 2004." Many non-profits that have relied on government funding have suffered deep and painful cuts in recent years, except for "faith-based" organizations that are newly eligible for federal funding. But as state and federal governments decrease their support for social services, charities are expected to pick up the slack even though they have smaller budgets to tackle bigger jobs.

We suspect two things have to happen to improve the outlook for U.S. charities: First, we must get the attention of the American public and show them how valuable our services are (especially for medically-disenfranchised people with unusual diseases and unusual problems). Secondly, we have to hope that there will be a true economic turnaround quickly. People who are worried that they may lose their job, or if they have no job, are unwilling or unable to donate to charity. When the economy is good charities prosper, especially at the end of the year when people think about tax deductions.

Ultimately, the major catastrophes that have drawn the public's attention and donations in the last few years have also taught an important lesson for all of us: The American public can be passionately humane and generous when it recognizes a worthy cause. Getting to the top of the public's list of worthy causes is the challenge!



## MEETINGS & PUBLICATIONS

The Tenth National HIPAA Summit: April 6-8, 2005, Baltimore Marriott Waterfront, Baltimore, Maryland. Contact: The Tenth National HIPAA Summit, Conference Office, 7790 Barbary Avenue, Yucca Valley, Ca 92284; phone: 1-800-684-4549 or (760) 365-0837; email: <[registration@hcconferences.com](mailto:registration@hcconferences.com)>.

10<sup>th</sup> Year Celebration of the LAM Foundation/Tuberous Sclerosis Alliance Research Conference: April 8-10, 2005, The Hyatt Regency, Downtown Cincinnati. Contact: The LAM Foundation, 10105 Beacon Hills Dr., Cincinnati, OH 45241; phone: (513) 777-6889; fax: (513) 777-4109; email: <[lam@one.net](mailto:lam@one.net)>; Website: <[www.lam.uc.edu](http://www.lam.uc.edu)>.

National Public Policy Summit on Lupus: "A Cure for Lupus is Within Reach: Research, Education, Advocacy, Communication, Healthcare: April 13-14, 2005, Washington Court Hotel, Washington, DC. Contact: Lupus Foundation of America, Inc., 2000 L. Street NW., Suite 710, Washington, DC 20036; phone: (202) 349-1155; fax: (202) 349-1156; email: <[info@lupus.org](mailto:info@lupus.org)>; Website: [www.lupus.org](http://www.lupus.org).

The Autism Research Institute 10<sup>th</sup> Anniversary Defeat Autism Now! (DAN!) Conference: "Science-Based Effective Treatments for Autism": April 14-17, 2005, Boston, Massachusetts. Contact: Autism Research Institute, 4182 Adams Avenue, San Diego, CA 92116; Further information available at: <[www.DanConference.com](http://www.DanConference.com)> or email: <[Danquestions@aol.com](mailto:Danquestions@aol.com)>; or call (609) 921-3717.

National Spasmodic Dysphonia Association (NSDA) 2005 Patient Symposium: April 16, 2005, Portland, Oregon. Contact: NSDA, 300 Park Blvd., Suite 350, Itasca, IL 60143; phone: (800) 795-NSDA; fax: (312) 803-0138; email: <[NSDA@dysphonia.org](mailto:NSDA@dysphonia.org)>; Website: <[www.dysphonia.org](http://www.dysphonia.org)>.

National Brain Tumor Foundation Conference: "Together in Hope": April 29-May 1, 2005, Intercontinental Hotel, Houston, Texas. For a complete program posting, call (713) 792-2222 or visit <[www.mdanderson.org/conferences](http://www.mdanderson.org/conferences)>.

Developmental Disabilities Nurses Association (D.D.N.A.) 13<sup>th</sup> Annual Conference: "Broadening Our Perspective: New Challenges in Developmental Disabilities Nursing": May 1-3, 2005, Hyatt Regency Columbus, Columbus, Ohio. Contact: D.D.N.A. 2005, 1733 H St., Suite 330 PMB 1214, Blaine, WA 98230; phone: (800) 888-6733; fax: (360) 332-2280.

YAI/National Institute for People with Disabilities 26<sup>th</sup> Annual International Conference: "Building Brighter Futures for People with Developmental and Learning Disabilities": May 9-12, 2005, Crown Plaza Manhattan Hotel, New York City. For more information, contact: Aimee Horowitz at (212) 273-6255; email: <[ahorowitz@yai.org](mailto:ahorowitz@yai.org)>; Website: <[www.yai.org](http://www.yai.org)>.

19<sup>th</sup> Annual Conference-Consortium of Multiple Sclerosis Centers (CMSC): "Navigating the World of Multiple Sclerosis": June 1-5, 2005, The Walt Disney World Swan and Dolphin Hotel, Orlando, Florida. Contact: CMSC, c/o Gimbel Multiple Sclerosis Center, 718 Teaneck Rd., Teaneck, NJ 07666; phone: (201) 837-0727; fax: (201) 837-0604 or (201) 837-9414; email: <[info@mscare.org](mailto:info@mscare.org)>; Website: <[www.mscare.org](http://www.mscare.org)>.

Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: "Strategies for Living Well": June 2-4, 2005, St. Louis, Missouri. Contact: Justine Craig-Meyer, Post-Polio Health International, 4207 Lindell Blvd. #110; St. Louis, MO 63108-2915; phone: (314) 534-0475; email: <[info@post-polio.org](mailto:info@post-polio.org)>; Website: <[www.post-polio.org](http://www.post-polio.org)>.

2005 National HIV Prevention Conference: June 12-15, 2005, Hyatt Regency Atlanta Hotel, Atlanta, Georgia. Contact: Centers for Disease Control and Prevention (CDC), 1600 Clifton Rd. NE, Atlanta, GA 30333; phone: (703) 548-0618; Website: <[www.info@2005HIVPrevConf.org](http://www.info@2005HIVPrevConf.org)>.

Mitochondrial Medicine 2005 Symposium: "Gateway to a Cure": June 15-18, 2005, Hyatt Union Station, St. Louis, Missouri. Contact: United Mitochondrial Disease Foundation, 8085 Saltsburg Rd., Suite 201, Pittsburgh, PA 15239; phone: (412) 793-8077; fax: (412) 793-6477; email: <[kara@umdf.org](mailto:kara@umdf.org)>; Website: <[www.umdf.org](http://www.umdf.org)>.

National Conference on Prostate Cancer 2005: "Exploring New Pathways: Sharing the Journey: June 16-19, 2005, Omni Shoreham Hotel, Washington, DC. For more



information and to register: Website: <[www.pcri.org](http://www.pcri.org)> or phone: (310) 743-02117.

The Scleroderma Foundation's National Conference:  
**June 18-20, 2005**, Hyatt Regency Hotel, Boston, Massachusetts. For information, contact: Scleroderma Foundation, 12 Kent Way, Suite 101, Byfield, MA 01922; Website: <[www.scleroderma.org](http://www.scleroderma.org)>.

United Leukodystrophy Foundation National Conference:  
"Love and Science 05": **July 20-23, 2005**, Dekalb, Illinois. Contact: United Leukodystrophy Foundation, 2304 Highland Dr., Sycamore, IL 60178; phone: (800) 728-5432 or (815) 895-3211; email: <[Janet@ulf.org](mailto:Janet@ulf.org)>; Website: <[www.ulf.org](http://www.ulf.org)>.

Immune Deficiency Foundation Third National Conference: **June 23-25, 2005**, Disney's Contemporary Resort, Lake Buena Vista, Florida. Contact: Immune Deficiency Foundation, 40 W. Chesapeake Ave., Suite 308, Towson, MD 21204; phone (800) 296-4433; fax: (410) 321-9165; email: <[idf@primaryimmune.org](mailto:idf@primaryimmune.org)>; Website: <[www.primaryimmune.org](http://www.primaryimmune.org)>.

The Alagille Syndrome Alliance 3<sup>rd</sup> International Symposium on Alagille Syndrome: **June 24-26, 2005**, Emory Conference Center Hotel, Atlanta, Georgia. Contact: Alagille Syndrome Alliance, 10500 SW Starr Dr., Tualatin, OR 97062; phone: (503) 885-0455; email: <[alagille@earthlink.net](mailto:alagille@earthlink.net)>; Website: <[www.alagille.org](http://www.alagille.org)>.

Penn State Neuroscience Research Conference:  
"Anxiety, Mood & Sleep Disorders: Role of Stress and Trauma": **June 30-July 2, 2005**, The Hotel Hershey, Hershey, PA. Contact: Central Pennsylvania Psychiatric Institute, Penn State College of Medicine, Dept. of Psychiatry, H073, PO Box 850, Hershey, PA 17033-0850; fax: (717) 531-1578; Website: <[www.pennstatecppi.com](http://www.pennstatecppi.com)>.

2005 National Alopecia Areata Foundation (NAAF) Conference: "A 20-Year Celebration By The Sea": **June 30-July 3, 2005**, Tampa Marriott Waterside Hotel, Tampa, Florida. Contact: NAAF, 14 Mitchell Blvd., San Rafael, CA 94903; phone: (415) 472-3780; fax: (415) 472-5343; email: <[info@naaf.org](mailto:info@naaf.org)>; Website: <[www.naaf.org](http://www.naaf.org)>.

Batten Disease Support & Research Association (BDSRA) Annual Conference: "Sailing Toward a Brighter Future": **July 21-24, 2005**, Columbus, Ohio. Contact: BDSRA, 120 Humphries Dr., Suite 2, Reynoldsburg, OH 43068; email: <[bdsra1@bdsra.org](mailto:bdsra1@bdsra.org)>.

The Sturge-Weber Foundation International Conference: **July 21-24, 2005**, Hershey, Pennsylvania. Contact: The Sturge-Weber Foundation, P.O. Box 418, Mt. Freedom, NJ 07970-0418; email: <[SWF@sturge-weber.com](mailto:SWF@sturge-weber.com)>; Website: <[www.sturge-weber.com](http://www.sturge-weber.com)>.

Second International Conference for Families Living with Exstrophy & Epispadias: **August 5-7, 2005**, Humber College, Toronto, Ontario, Canada. Contact: Karen Moseley at 1-866-300-2222 (toll-free) or (760) 386-9254; email: <[admin@bladderexstrophy.com](mailto:admin@bladderexstrophy.com)>; Website: <[www.bladderexstrophy.com](http://www.bladderexstrophy.com)>; or by mail: P.O. Box 101523, Fort Irwin, CA 92310.

1<sup>st</sup> National Lymphedema Network International Patient Summit: "Lymphedema –Building Pathways to Health & Wellness": **August 18-20, 2005**, John Ascuaga's Nugget Hotel & Resort, Sparks/Reno, Nevada. Contact: National Lymphedema Network (NLN), 2005 NLN Patient Summit Secretariat Latham Square, 1611 Telegraph Ave., Suite 1111, Oakland, CA 94612-2138; phone: (510) 208-3200; Website: <[www.lymphnet.org/2005summit/ptsummit05.html](http://www.lymphnet.org/2005summit/ptsummit05.html)>.

Aplastic Anemia & MDS International Foundation 19<sup>th</sup> Annual Patient & Family Conference: "Bone Marrow Failure Scientific Symposium": **October 17-19, 2005**, Loews L'Enfant Plaza Hotel, Washington, DC. Contact: Aplastic Anemia & MDS International Foundation, Inc., P.O. Box 613, Annapolis, MD 21404-0613; phone: (800) 747-2820 or (410) 867-0242; fax: (410) 867-0240; email: <[baker@aamds.org](mailto:baker@aamds.org)>; Website: <[www.aamds.org](http://www.aamds.org)>.

**Note: Please notify NORD of any address, phone, fax, or email change so we can keep our contact information current.**