

REMINDER: If you are planning to attend the VOR events in Washington, D.C., the deadline for hotel reservations is coming up quickly: May 12. Call 866-Affinia (866-233-4642) (toll-free) to make reservations (reference: VOR).  
BE A SPONSOR!: See attached or <http://vor.net/2008Sponsorship.htm> and YOUR HELP IS APPRECIATED!

Join Us! Help Commemorate VOR's 25th Anniversary!!  
VOR will host its Annual Meeting, Washington Initiative, Special Anniversary Celebration, and the 2nd Annual Capitol Hill reception, beginning June 13, 2008 in Washington, D.C. Visit <http://vor.net/2008AnnualMeetingandInitiative.htm> for more information on the Annual Meeting and Initiative.

Be a Sponsor / Get a Sponsor: Select a sponsorship category you would like to support! Help with the Capitol Hill Reception expenses, support the 25th Anniversary Reception, help fund the successful day-long Annual Meeting, including breakfast, lunch, speaker sessions, participant handouts, help with the expenses for the critically important Washington Initiative, and more! See <http://vor.net/2008Sponsorship.htm> ( <http://vor.net/2008Sponsorship.htm> ) for details.

Questions? Contact Tamie at [Tamie327@hotmail.com](mailto:Tamie327@hotmail.com) or 605-399-1624.

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VOR Weekly E-Mail Update  
May 2, 2008  
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FEDERAL BILL / ISSUES UPDATE

1. H.R. 3995 update - The number of cosponsors is growing. Is your Rep on the list?
2. House passes veto proof Medicaid Regulation Moratorium bill; Senate is considering - calls needed.
3. COPAA Call to Action: Support the H.R. 4188, the Idea Fairness Restoration Act
4. House panel unimpressed by disability backlog reeducation
5. Senate unanimously passes genetic nondiscrimination bill.

Next week: State News

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1. H.R. 3995 update - The number of cosponsors is growing. Is your Rep on the list?
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If your Representative is not listed as a cosponsor yet, contact your Representative today. Please call even if you have called before. Ask for the Health LA. Ask that your Representative COSPONSOR H.R. 3995.

H.R. 3995, if passed, will require that before federally-financed class action lawsuits against Medicaid-certified and funded ICFs/MR can proceed, residents and guardians must receive notice of the lawsuit and be given a time-limited opportunity to opt-out of the proposed lawsuit, or do nothing and join in.

Visit <http://vor.net/HR3995ActionAlert.htm> for additional H.R. 3995 information.

Contact Tamie with any questions and to receive H.R. 3995 advocacy materials (605-399-1624; [tamie327@hotmail.com](mailto:tamie327@hotmail.com)).

Visit <http://www.congress.org> to find out who your Representative is and for contact information.

CALL TODAY

H.R. 3995 Cosponsors so far:

Rep. Charles Boustany, Jr. (D-LA)

Rep. Steve Cohen (D-TN)

Rep. Michael Capuano (D-MA)  
Rep. Bob Etheridge (D-NC)  
Rep. Bob Filner (D-CA)  
Rep. Charles Gonzales (D-TX)  
Rep. Stephen Lynch (D-MA)  
Rep. John Larson (D-CT)  
Rep. Doris Matsui (D-CA)  
Rep. James McGovern (D-MA)  
Rep. Brad Miller (D-NC)  
Rep. James Moran (D-VA)  
Rep. Ron Paul (R-TX)  
Rep. Todd Platts (R-PA)  
Rep. Ted Poe (R-TX)  
Rep. Christopher Shays (R-CT)  
Rep. Pete Stark (D-CA)  
Rep. Tim Walberg (R-MI)  
Rep. Carol Shea-Porter (D-NH)  
Rep. Debbie Wasserman Schultz (D-FL)  
Rep. Lynn Woolsey (D-CA)

Pending: These offices have directly asked to be added as cosponsors, but have not yet been officially added: Rep. Gary Miller (R-CA) and Rep. Peter Roskam (R-IL).

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2. House passes veto proof Medicaid Regulation Moratorium bill; Senate is considering - calls needed.

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Source: Families USA, e-updates from Monday, April 28 and Tuesday, April 29:  
The Administration has proposed seven (7) Medicaid regulations that could have a serious impact on the ability of people with disabilities to access critical services. In addition to concerns about the impact of these regulations, some states have alleged in a lawsuit that the Administration went beyond its rulemaking authority with these regulatory proposals.

Congress has responded by introducing H.R. 5613, the Protecting the Medicaid Safety Net Act, which responsibly suggests that implementation of these regulations be put on hold until the real impact on beneficiaries can be studied.

Last week, the House overwhelmingly passed H.R. 5613.

On Monday, April 28, Senate Majority Leader Reid "hotlined" H.R. 5613, the Protecting the Medicaid Safety Net Act, meaning he asked for unanimous consent so that the Senate can proceed to the immediate consideration of a bill, bypassing Senate Finance Committee consideration. Any Senator can object, and we understand that Senator Grassley (Ranking Member of the Senate Finance Committee) already did. We believe Reid's action was in response to efforts by HHS Secretary Leavitt and others to obstruct Democrats from quickly passing this bill. Senator Reid's move sends a strong message about the Democratic leadership's support for moving all seven regulations together and to move this bill forward in a timely manner.

TO SUPPORT PASSAGE OF H.R. 5613, click here -

[http://ga3.org/campaign/badmedicine\\_email](http://ga3.org/campaign/badmedicine_email)

( [http://ga3.org/campaign/badmedicine\\_email](http://ga3.org/campaign/badmedicine_email) ) - for a FAMILIES USA action alert.

For more information about the seven Medicaid regulations visit,

<http://www.kff.org/medicaid/7739.cfm>.

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3. COPAA Call to Action: Support the H.R. 4188, the Idea Fairness Restoration Act

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(Note: This is being shared for your information. VOR does not have a position on H.R. 4188).

The Council of Parent Attorneys and Advocates ([www.copaa.org](http://www.copaa.org)) a national voice for

special education rights and advocacy, is coordinating a national call in day on Tuesday, May 6, to seek support for H.R. 4188, the Idea Fairness Restoration Act.

This bill will allow parents who prevail in due process or litigation under IDEA recover their expert witness fees. The bill would override the Supreme Court's decision in Arlington Central School District v. Murphy (2006) and allow parents who prevail in due process or litigation to be reimbursed for their expert witness fees. When prevailing parents cannot recover expert costs, the playing field is neither level nor fair, and children are denied a free appropriate public education and other fundamental IDEA rights. School districts can use tax dollars to employ and pay for psychologists and other paid experts. Parents have fewer resources and yet must bear a greater financial burden.

H.R. 4188 was introduced by Congressman Chris Van Hollen (Maryland) and Pete Sessions (Texas), it will help level the playing field for the parents of millions of children with disabilities.

The Council of Parent Attorneys and Advocacy is asking everyone in support of H.R. 4188 to call Congress on Tuesday, May 6, 2008 and ask them to Cosponsor H.R. 4188: 202-224-3121

For more information, see <http://www.copaa.org/pdf/MurphyBrochure.pdf>

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#### 4. House panel unimpressed by disability backlog reduction

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CongressDailyPM - Wednesday, April 23, 2008

By Elaine S. Povich

Social Security Commissioner Michael Astrue said today his agency is making progress in cleaning up the huge backlog of disability cases, but that the task will still be long and difficult, and cannot be accomplished if Congress wavers on increasing its budget. Astrue said he has "significant hope" for more progress in the coming year, with the goal of eliminating the tens of thousands of backlogged cases by 2013.

"We are trying to beat that goal," he told the House Ways and Means Committee. One of the steps the agency is taking is increasing the number of administrative law judges who handle disputes about disability claims from 150 to 175, Astrue said. That increase should step up the pace, he said.

Members noted the Social Security administrative budget was cut significantly between 1999-2007. For FY08, Congress appropriated \$148 million over the president's request, but still short of the \$10.1 billion requested by the Social Security Administration. Astrue said with additional funds and additional personnel, the agency can begin to tackle the backlog, which has resulted in some disability cases dragging on for 1,000 days before they are settled. Meanwhile, the people claiming disability are getting sicker or more disabled, according to committee members.

I want everyone go have a sense of outrage because our constituents who file these claims have every right to feel outraged, said Rep. Sander Levin, D-Mich. "What do we say to someone who has been waiting two years?"

In response, Astrue said his agency is making progress in cutting down the backlog of cases which members of Congress said now includes 1.3 million individuals. He said the number of cases being settled now exceeds the number of new cases being filed and that productivity is up 10 percent.

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#### 5. Senate unanimously passes genetic nondiscrimination bill

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Source: AADMD, 4/25/08

The Wall Street Journal (4/25, A11, Zhang, Wang) reports that with a unanimous vote of 95 to 0, the Senate approved "landmark legislation barring insurers and employers from discriminating based on a person's genetic makeup, a move many employers dislike but one that could accelerate both genetic testing and research on personalized

medicine." Next week, the "same bill is expected to sail through the House...and on to President Bush, who is expected to sign it."

According to the Los Angeles Times (4/25, Alonso-Zaldivar), the Genetic Nondiscrimination Act "does more than protect those who undergo genetic testing: It marks a significant milestone in the effort to develop a 21st century architecture of laws to govern the revolutionary changes sweeping science and medicine." The Times calls the bill "notable because while scientific changes are occurring at a rapid pace, agreement on how to deal with the consequences is lagging."

The AP (4/25, Abrams) adds that there are currently "more than 1,100 genetic tests available." These "test[s] could lead to early, lifesaving therapy for a wide range of diseases with hereditary links such as breast and prostate cancer, diabetes, heart disease, and Parkinson's disease."

The Baltimore Sun (4/25, Rockoff) explains that the "legislation would bar health insurers from using genetic information to deny coverage or raise the rates on customers. It would also prevent employers from hiring, firing or placing employees based on the information." Furthermore, "[n]either insurers nor employers could require genetic testing."

Bloomberg (4/25, Waters, Marcus) notes that the bill may "remove an obstacle that keeps some people from getting tested to find out whether they have a high risk of developing diseases."

Under the bill, insurers who are found to have "violat[ed] consumers' genetic privacy" can "be fined up to \$500,000." The bill also "prevents medical insurers or employers from requiring genetic tests as a condition of coverage or employment," WebMD (4/24, Zwillich) points.

Modern Healthcare (4/25, Lubell), Reuters (4/25, Dunham), Scientific American (4/24, Watson, Crick), Congressional Quarterly (4/25), The Hill (4/25, Alarkon), and the BBC (4/25), also cover the story.

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Tamie Hopp

REFERRAL/MEMBERSHIP/CONTRIBUTION FORM

THREE EASY WAYS TO SUPPORT VOR > REFER, CONTRIBUTE OR JOIN

THANK YOU FOR YOUR SUPPORT!

TO JOIN OR CONTRIBUTE: \$25 per individual, \$150 per family organization, or \$200 per provider/professional organization. Extra donations are welcome!

You may pay by credit card or check.

TO REFER SOMEONE TO VOR: Use the form below, including the additional sections for referrals.

Mail the completed form (if joining or contributing) with payment to:

Voice of the Retarded

836 S. Arlington Heights Rd., #351

Elk Grove Village, IL 60007

847-258-5273 fax (for referrals or credit card payments)

kluck146@comcast.net (for referrals or credit card payments)

FOR REFERRALS: \_\_\_ The contact information provided is for someone I think would consider membership with VOR.

FOR REFERRALS: \_\_\_ You may use my name in any correspondence with this individual. My name is \_\_\_\_\_.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Address (if paying by credit card, use billing address). All forms must include complete address including zip code)

\_\_\_\_\_  
City St Zip

\_\_\_\_\_  
Phone Fax

\_\_\_\_\_  
E-Mail

\_\_\_\_\_  
Family/Professional Organization Affiliation (if applicable)

VOR now accepts Master Card and Visa. If paying by credit card, please provide the following information:

Amount to charge to card:

\_\_\_\$1,000 \_\_\_\$500 \_\_\_\$250 \_\_\_\$150 \_\_\_\$50 \_\_\_\$25

\$\_\_\_ Other amount

\_\_\_ Mastercard

\_\_\_ Visa

Card Number: \_\_\_\_\_

Expiration Date: \_\_\_\_\_

Cardholder's Signature: \_\_\_\_\_

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