

**“Health Reform and You: An Opportunity to Have Your Questions Answered by Health Reform Experts”**

MDA Public WebEx — September 29, 2010

Guest Presenters: Allison Kassir and Laura Loeb of King & Spalding

**Questions & Answers**

Prior to the WebEx, participants sent questions to the presenters; provided below are the questions submitted by members of the MDA community, along with answers offered by our esteemed presenters. Please forward additional questions to [advocacy@mdausa.org](mailto:advocacy@mdausa.org).

**Q: I would like to know if my DME allotment of \$1,500 per year would change with the reform or if the company I work for would need a different rider to their policy. Without a special rider for special therapies, my policy currently only covers 90 physical therapy visits. Will the reform change that?**

A: Unfortunately, we will continue to see plans with annual and lifetime limits for services that are not deemed “essential health benefits.” The new health care reform law only prohibits annual and lifetime limits for “essential health benefits.” The statute defines “essential health benefits” as doctor visits, hospitalizations, prescription drugs, chronic disease management, and rehabilitative services and devices. We will have to see what the implementing regulations will look like in further defining what is meant by “chronic disease management” and “rehabilitative services and devices.” It’s possible that some of the DME that MD patients need will fall under those categories. I think we can make a good argument that the DME that we need is “essential” — including physical therapy for chronic disease management.

Currently, there are no regulations further defining what are “essential health benefits.” Annual limits in plans on DME and physical therapy will currently remain because clearly not all DME or physical therapy will qualify as “essential health benefits.” Therefore, we may have to appeal denials of DME or physical therapy based on annual limits, but ultimately I believe we will be able to prevail by arguing that the DME and PT that MD patients need qualify as “essential health benefits.”

Thus, we encourage you to appeal when necessary and let the local MDA teams know of the certain types of benefits not being covered.

**Q: Will health care reform help people with neuromuscular disease obtain health insurance that is reasonably priced? Is Medicaid the only way to get daily assistance with independent living with such disabilities?**

A: Premiums for the new pre-existing insurance plans run by the federal government as a result of health care reform range from \$320 to \$570 a month. So, as I noted in my presentation, new plans are available for the uninsured, but they are not inexpensive. For low income individuals and families, Medicaid will continue to be the best way to get daily assistance for people with a disability.

In addition, the HCR (health care reform) law has provisions for state grants (currently about 24 states have them in place) to assist disabled individuals and caregivers in accessing treatment.

The Department of Education or the Department of Developmental Disabilities can also assist in some states. Contact your local MDA team for details.

**Q: Obviously, all of us with MD are not eligible for currently available long-term care insurance plans. Wasn't there something in the health care act about offering such policies to Medicare recipients and would MD patients be eligible?**

A: There is nothing in the HCR law that affects LTC insurance plans. MD patients may not be eligible at this time, but HCR did enact the Community Living Assistance Services and Supports (CLASS) Act, which will be available eventually (however, it does not start enrollment until 2012, and benefits aren't available until 2017). We still have an issue here that will need to be addressed. Even when implemented in 2017, the benefit will be a cash payment, averaging only around \$50 per day.

A New Jersey congressional member is currently focusing on LTC and CLASS — looking to expand access.

**Q: Regarding the new health reform regulations and the transition to adult services, my question is related to Medicaid (Medical Access in PA). My son has a neuromuscular disease and will soon be turning 18 (and going to college next fall). I will be calling Social Security in October to set up a phone interview for SSI. My understanding is that once on SSI, he will be able to continue with his Medicaid coverage. Now, with health reform allowing children to stay on primary insurance until age 26, how will that impact his eligibility for the Medicaid waiver through SSI?**

A: The HCR law should not affect Medicaid eligibility through SSI. If your son qualifies for SSI, he also will qualify for Medicaid. Medicaid would be secondary if he would be covered under your private insurance plan. Pennsylvania is a state where SSI and Medicaid are the same application. If eligible for SSI, individuals will automatically receive Medicaid in Pennsylvania. As children become adults, they also will be able to stay on the family's private insurance plan until age 26 if the family has such a plan. Will this affect Medicaid? The answer is no. Medicaid would be the secondary insurer.

**Q: How will the research and access to stem cells change under this bill?**

A: The HCR law will not affect research and access to stem cells.

**Q: I was diagnosed with ALS in January 2010. I am no longer working, and I received Social Security Disability and Medicare effective July 1, 2010. My husband will start a new job with a different company on October 1, and we will pay for COBRA through his old job for at least a month to ensure continuous coverage. I have two questions.**

- **My husband's new company also has Blue Cross but not the same Blue Cross of North Carolina that his old company had. Since I have a terminal illness, will the new Blue Cross be required to cover me?**
- **Under the new September 23 insurance changes, can the new Blue Cross company legally assert a waiting period for pre-existing illnesses like ALS?**

A: You should be eligible for coverage with the new insurance company with an ALS diagnosis. However, it is possible that the new plan has a waiting period for pre-existing conditions, as the federal

prohibition on that is being phased in. But, there also might be a state prohibition on this waiting period, so you should check on that. Even if no state protection, if this is a problem, appeal any denials! COBRA will aid until the new plan is in effect, and it appears that you also have Medicare coverage. The pre-existing condition insurance plan under the HCR law is also available, but you have to be uninsured for six months before that would kick in.

Be sure to access all the services available to you through the MDA clinic, which will not be impacted by this. MDA is not an insurance program, but our goal is to ensure access to quality care. Even if there is a lapse in your current coverage, talk with your MDA clinic director and your local MDA team to see what services are available and make sure that there are no lapses.

**Q: For people with a disability, what DME will be covered and will it be more affordable with the new law? Also, how will the cost of equipment impact us?**

A: Outside of the HCR law, there is a Medicare Competitive Bidding program going into effect, separate from HCR that should lower DME costs not only for Medicare beneficiaries but ultimately for everyone. It is currently difficult to determine with HCR what the limits will be for DME coverage. Even though we may have to fight to eliminate DME annual limits on coverage, this may be a winnable battle, arguing that DME for MD patients is an “essential health benefit.”

In addition, MDA has an equipment loan program, which is not intended to replace insurance but assist in obtaining DME. This service also includes repairs. Contact your local MDA team for details.

**Q: I was recently laid off and doing temp work ever since. Since there's been over a one-year lapse in coverage, I'm concerned that there will likely be a pre-existing clause when I return to work full time and have health insurance available to me. I was wondering if the new reform addresses this or has done away with these “exclusions,” or lapses of care for pre-existing conditions?**

**The issue also was raised regarding lack of insurance and drugs that are cost prohibitive.**

A: The HCR law will be a benefit through the pre-existing condition insurance plan, which you would be eligible for since you have been without coverage for at least six months.

In addition, many drug manufacturers have patient assistance programs that may be available as a resource for you. After accessing the drug company, talk with your local social worker and MDA clinic physician.

**Q: Now that the HCR law is in effect, will I now have to see a predetermined doctor that is specified by the federal government or can I continue to see the physicians I know and trust?**

A: In Medicare fee for service or any private nonmanaged care plan, you can see any doctor, and this is unchanged by HCR. If in a managed care plan, you will continue to have in-network and out-of-network providers. There is nothing in the HCR law regarding this historical problem with managed care plans providing better coverage for in-network physicians. But if right now you can see any physician you want to under your plan, this will not change under HCR.

**Q: I have CMT and am on Social Security Disability with limited income and relying on Medicare for medical assistance. How will the HCR law help or hinder my health care? Also, I did not get a cost of living increase, but it seems our medical costs will continue to increase. How can I expect to receive good medical care when my daily living expenses continue to increase and my medical premiums continue to increase?**

A: This is a huge problem — we are bracing ourselves to see what premium increases will be for 2011. Under HCR, insurance plans now have to justify proposed premium increases as “reasonable” to federal and state officials. However, it seems likely that premium increases of some level will be considered “reasonable.” Maybe even premium increases as high as 7 to 8 percent. Most premiums will go up even though there are no cost of living increases for many wage earners. Medicaid may assist, especially with expansion packages. Clearly, the administration has a lot at stake here to try to ensure that health care insurance premiums are not allowed to increase by exorbitant amounts.

**Q: Regarding genetic testing, if you are tested for a neuromuscular disease, can you be denied insurance coverage? Does HCR law protect us from being denied insurance or charged higher premiums if we are diagnosed with, or are carriers of, a neuromuscular disease?**

A: It is against the law for this kind of thing to occur. This situation is protected by GINA, the Genetic Information Nondiscrimination Act. You can pursue genetic testing and not be afraid — know your rights. However, please note that this applies to medical insurance and not life insurance. It is still legal for life insurance companies to deny coverage based on the results of genetic tests.

**Q: My son has an individual insurance policy through Blue Cross. I have been told by the insurer that the health reform’s elimination of the “lifetime maximum cost sharing” (\$2 million) does not apply, or is not the same as, the lifetime maximum limit put on genetic testing (\$5,000). Is that accurate and can you please explain?**

A: Yes, the prohibition in HCR on lifetime limits only applies to lifetime limits on “essential health benefits.” Genetic testing will not be considered an “essential health benefit” and, therefore, will not be protected by this prohibition.

**Q: I am 57 with LGMD and retired from a teaching position. I am not approved for SSDI and not over 65. Regarding the pre-existing health care plan for those without insurance for six months, what do I do in the interim six months?**

A: If COBRA expires, you need to wait six months. This six-month waiting period is a serious flaw in HCR. Prescription drug manufacturers have patient assistance programs that may be of assistance during this waiting period. Otherwise, the state may have some programs available. There also may be retiree health benefits available, but from the question, it sounds like that is not an option for you. However, you can still attend the MDA clinic and see a physician; MDA also will pay for your flu shot, which in one shot now covers seasonal flu and H1N1.

**Q: Will those with muscular dystrophy and others that are in need of orthotic devices be able to have them changed more often as needed? Currently, those who have atrophied muscles or those who have lost an enormous amount of weight cannot get new orthotics more often than every three years. Are changes in this reform bill to cover such occurrences?**

A: You should be able to argue, as we have discussed in previous questions, that these orthotic devices qualify as an “essential health benefit” and, therefore, there should be no annual limit on their coverage. You might have to appeal a plan that tries to argue that these orthotics are not “essential health benefits,” but I think you should be able to win this on appeal. You might have to appeal this all the way to an administrative law judge. The appeal mechanism will be better through the HCR law. MDA also has \$500 per year available January through December for equipment repairs. Contact your local MDA team for more information.

**Q: My mother has MD, and I want to know with the new health care reform, is she going to be able to visit not only her practitioner but specialized doctors as well? She sees a cardiologist, internist, neurologist and urologist. Will those doctors be part of her plan at no charge or a small fee?**

A: Nothing changes with respect to Medicare or employee-based insurance in the HCR law. HCR itself does not affect seeing various professional disciplines if your mother saw these specialists under her old plan.

**Q: Does the new bill include dental as a free medical or 80 percent pay for those with disabilities on Medicare?**

A: There is nothing in the HCR law regarding Medicare-covered dental services.

**Q: Why is a person not eligible for Medicare until two years after Social Security Disability Insurance begins?**

A: This has been a problem for decades. The law is currently set up this way with the two-year waiting period, which the government uses to determine that someone is permanently disabled. However, there are a few exceptions to this two-year waiting period. ALS is fast-tracked, for example. Regarding this issue, we need statutory and regulatory changes.