

Testimony of Nathan Wilkes

Hearing on "Insured But Not Covered: The Problem Of Underinsurance"

House Energy and Commerce Committee

Subcommittee on Oversight and Investigations

October 15, 2009

2123 Rayburn House Office Building

Mr. Chairman and Members of the Subcommittee, my name is Nathan Wilkes and I am from Englewood, Colorado. Thank you for the opportunity to talk to you today about the difficulty my family has had in maintaining health insurance due to the high cost of the treatment my son, Thomas, needs to live a healthy life. Our family has come up against lifetime limits or caps in our insurance policies more than once and this occurred before Thomas was 4 years old. I have been able to maintain insurance coverage, but it has been a struggle and a constant worry for my family and me. Today, I would like to tell you a little bit about how I managed to deal with lifetime caps, which I believe is an insurance practice that discriminates against individuals with high cost chronic conditions, like my son. I would also like to ask you for your help in immediately eliminating this practice in all health insurance policies as part of the health reform legislation that is being considered by Congress.

My son Thomas was born in 2003 and was diagnosed with severe hemophilia A the day after he was born. Hemophilia is a genetic blood-clotting disorder that prevents his body from creating clots when he sustains injury. Contrary to general belief, the risks to bleeding are not from superficial cuts, but rather internal bleeding – such as bleeding into joints which causes pain, swelling, and joint damage (arthritis) and bleeding into the brain which can cause neurological damage or could be fatal. Thomas's bleeds must be treated quickly and aggressively to prevent irreversible long-term damage and painful disability.

Fortunately, we discovered that we lived close to one of the leading Hemophilia Treatment Centers in the country. The Mountain States Regional Hemophilia and Thrombosis Center provides a comprehensive disease management program for people living with hemophilia. This high standard of care is essential to Thomas living a healthy and productive life. Thomas was prescribed a treatment known as factor replacement therapy or clotting factor. These treatments are very effective, but very expensive. As a newborn, we would only need to treat him when he had a bleed, but the cost each time he was treated was at least \$1,000.

On the day Thomas was born, our local hematologist came by to help us comprehend what we were facing. Her first question to us was: Do you have good insurance? At the time, I was working in the telecommunications industry and my company, Virela Communications, offered excellent health insurance.

In 2004, when Thomas was 7 months old, he developed an inhibitor to his clotting factor replacement therapy. An inhibitor meant that his body developed an immunological response to the life-saving factor treatments that normally allowed his blood to clot if he had an injury. This meant two things: 1) we had to start immune tolerance therapy – giving Thomas regular doses of Factor VIII and 2) if Thomas did have a bleed, we had to use a more expensive treatment therapy to stop the bleed. As a result, claims for 2004 were very high, approximately \$500,000.

In 2005 and 2006, Thomas's treatment increased, costing around \$750,000 per year. During this period the premiums for my company's insurance policy with United Healthcare increased and when my company sought to renew its policy in 2006, we

were only offered a more expensive and more restrictive policy with a \$1 million lifetime cap. In late 2005, when the lifetime cap was announced for 2006, working with my company's HR director and the insurance broker, we tried to see if there was anything we could do to get it removed, get a waiver, or find another way to work around it. Despite my employer's best efforts, there was nothing that could be done.

The introduction of the cap for the 2006 plan-year started a timer that couldn't be reversed. I recognized that when, not if, we hit the cap, I would have to make critical decisions related to my work, my family and lifestyle. To go without insurance for even a few months would put us into a "pre-existing condition" category due to my son's hemophilia and our access to insurance would be severely compromised.

I knew I would have to find some way to maintain private insurance coverage. Over the next few months we considered our options:

- 1) Quit my job and work for a larger company or the government with a larger risk pool, where my claims would not be noticed as quickly.
- 2) Have my wife go to work and shift our children to her new employer's plan. We felt that this would only shift the problem temporarily and we would then need to put our three children into childcare which was costly and something we did not want to do.
- 3) Turn to Medicaid for Thomas. By all accounts, Colorado is one of the most difficult states in which to get on to Medicaid. Since we "earn too much money," the only option would be through a waiver program. We did start this process, but his qualification was not certain and the waitlist at the time was around five years. A wait of five days would be a problem for us – five years was out of the question.
- 4) Get divorced and have my wife – earning no income – qualify for Medicaid. A social worker told us that others have done this in order to provide health insurance for their children. While this would be a "paper divorce," it was not an option we would consider.
- 5) Put Thomas on our state's high risk pool, CoverColorado, which has a \$1 million cap. At the current rate of claims, this would have been a short-term fix, where we would likely hit the cap in 6-18 months.
- 6) Start my own consulting business as an employer of two, thus falling into the small group insurance category and being able to select from all small-group plans thanks to guarantee-issue requirements.

In April 2007, Thomas, who was almost 4 years old, hit the \$1 million lifetime cap of our employer-based insurance policy with United Healthcare. Our only option was to enroll him in the state high risk pool, CoverColorado. We worked with CoverColorado for months in preparation, but they couldn't accept him until he officially reached the cap. To make sure that we would not have a gap in coverage we tried to track our cap on a

daily basis. Although we were in constant contact with United Healthcare they could never accurately tell us exactly how close we were to reaching the cap – even in the final few days of being covered. In the end, the inability of United Healthcare to help coordinate our claims left us with significant out-of-pocket expenses.

For the next year, Thomas was covered under CoverColorado and the rest of our family had separate coverage. During this time, we were paying over \$25,000 per year in premiums, deductibles, and other out-of-pocket expenses for insurance and medical care. We were paying two sets of premiums and deductibles – one to CoverColorado for Thomas and another for the employer-based coverage for the rest of the family. This hardship on our family left us fighting to keep up with bills and forced us to rely on credit and home equity to stay afloat. The more credit we used, the worse our credit ratings got. The worse our credit ratings got, the more we ended up paying for everything as our interest rates climbed. Harassing collections agencies began calling as we struggled to get providers paid.

We spent over a year setting up our own business so that in May 2008, when my son had nearly exhausted CoverColorado's \$1 million lifetime cap, we would be able to pull him into our new company's group coverage. I had to quit my job, even though my employer tried everything they could to find another solution to our health insurance needs that would enable me to stay on as an employee. In addition to considerable accumulated medical debt prior to this juncture, quitting a good-paying job, taking a pay cut, and starting a business also took their toll, but I could not fail.

Our family is now covered by a high deductible health plan with a \$6 million cap, premiums of roughly \$10,000 per year, and an annual deductible of \$6,000. It is only a matter of a few years before we reach the end of that road and have to change course once again. However, one single significant event between now and then could destroy our currently tenuous security. Injury, death, loss of work contract income, or even reversal of the 2008 state law that instituted modified community rating in Colorado (preventing significant rate-up due to health status) would have a disastrous effect for us.

Attached to my written testimony is a chart that shows the insurance premiums and benefits from my previous employer since 2002. After my son's high dollar claims started in 2004, a significant change in coverage for 2005 occurred, with the cost of coverage rising approximately 35%. When this occurred my previous employer tried to find another insurer to cover the company, but to no avail. United Healthcare was required to continue to sell the company insurance, but in order to keep the basic premiums down for employees, my company offered us a high deductible health plan with a small investment in our health savings accounts to help us afford the coverage.

After my son came off of my employer's health plan in April 2007, benefits improved and the premium actually decreased in 2008. According to my former employer, in 2009 not only did cost-sharing improve again, but they were also able to once again offer a PPO plan and not just the high deductible plan. Also, premiums had decreased by 25% in the two years since my son was no longer covered under the plan.

The point I want to make here is that the impact of the high cost of Thomas' care was not just felt by my family, but by everyone I worked with. There were only 150 employees in the firm. Moving to the high deductible health plan had a huge impact on my co-workers. Families without funded health savings accounts put off going to the doctor for both preventive and acute care because they couldn't afford it. One co-worker had a friend sew up a laceration on his kitchen table because he couldn't pay for an ER visit. A young man, who had just started with the firm, had to put over \$9000 onto credit cards in order to pay for the delivery of his child by C-section. All of these changes must be remembered in the context of the faltering economy over the past few years, which made these changes particularly difficult for my co-workers and their families.

As you have heard today, maintaining health insurance has been a struggle for our family, but it has allowed me to provide my son with the lifesaving treatment he needs. Thomas is now 6 and very healthy, but without reforming the existing private insurance system in this country this struggle will continue for me. Health reform is critically important to me and the many other individuals and families that face high health care costs due to chronic conditions. I am pleased to see that the health reform legislation being considered would eliminate several discriminatory insurance practices such as pre-existing condition exclusions and annual and lifetime caps, but I am concerned that for those of us currently insured these changes will not take effect in existing plans until 2018. This is simply too long for my family to wait.

HR 3200 eliminates lifetime caps in the new qualified health benefit plans offered through the Exchange or through new employer-based plans as of 2013, but existing group plans are exempt from this requirement until 2018. As the Committee working directly on this bill, I ask you to not delay and immediately eliminate lifetime caps in existing insurance plans. The National Hemophilia Foundation, along with 30 other organizations representing individuals with chronic diseases and high cost conditions is seeking this change, which is similar to the provision in HR 3200 that prohibits insurance policy rescissions immediately. Both rescissions and lifetime caps are insurance company practices that penalize people who submit high-cost claims. Rescissions may have a more immediate impact since they occur following the submission of claims, but the end result is the same: a person with a serious medical condition loses insurance coverage.

I would like to submit for the record a letter sent to Chairman Waxman requesting the immediate elimination of lifetime caps in HR 3200 and a study by PricewaterhouseCoopers that estimates a savings to both Medicaid and Medicare if lifetime caps are eliminated.

Our country needs health insurance reform. My family needs health insurance reform, which would bring a future without annual or lifetime caps on benefits. My family is thankful for the Congressional efforts to eliminate lifetime caps on benefits in health reform.

Thank you.

# Health Care Premium Summary — Virtela Communications

\* 2005-2007 Employee contribution for Premium ONLY. Does not include Employee HSA Contributions.

Annual cost of Health Care Premiums per Participant Status	2000 BCBS (High)		2001 Cigna HMO		2002 Cigna HMO		2003 UHC PPO		2004 UHC PPO		2005 UHC PPO		2005 UHC HDHP/HSA		2006 UHC HDHP/HSA		2007 UHC HDHP/HSA		2008 UHC HDHP/HSA	
	Total Annual Premium	Annual Employee Contribution	Total Annual Premium	Annual Employee Contribution	Total Annual Premium	Annual Employee Contribution	Total Annual Premium	Annual Employee Contribution	Total Annual Premium	Annual Employee Contribution	Total Annual Premium	Annual Employee Contribution*								
Employee Only					\$ 2,142.00	\$ 623.28	\$ 2,434.92	\$ 623.22	\$ 2,676.84	\$ 669.24	\$ 3,649.62	\$ 1,950.00	\$ 2,373.80	\$ 390.00	\$ 3,073.20	\$ 390.00	\$ 3,545.62	\$ 390.00	\$ 3,545.62	\$ 390.00
Employee/Spouse	Couldn't find records for 2000-2001 and HR Director hasn't located this data yet.				\$ 4,862.16	\$ 1,414.70	\$ 5,527.20	\$ 1,414.66	\$ 6,076.44	\$ 1,519.08	\$ 8,284.90	\$ 3,900.00	\$ 5,388.76	\$ 780.00	\$ 6,976.32	\$ 1,040.00	\$ 8,048.82	\$ 1,040.00	\$ 8,048.82	\$ 1,040.00
Employee/Children					\$ 4,583.88	\$ 1,333.82	\$ 4,869.84	\$ 1,333.54	\$ 5,728.32	\$ 1,432.08	\$ 7,810.14	\$ 3,900.00	\$ 5,079.88	\$ 780.00	\$ 6,576.70	\$ 1,040.00	\$ 7,587.58	\$ 1,040.00	\$ 7,587.58	\$ 1,040.00
Family	\$ 468.00		\$ 494.00		\$ 7,047.00	\$ 2,050.47	\$ 8,010.72	\$ 2,050.36	\$ 8,806.68	\$ 2,201.64	\$ 12,007.32	\$ 4,810.00	\$ 7,809.88	\$ 1,170.00	\$ 10,110.88	\$ 1,820.00	\$ 11,664.90	\$ 1,820.00	\$ 11,512.54	\$ 1,820.00
Annual % Increase	These include maximum HSA contributions for HDHP years.						14%		10%		36%	2005 options	34%		19%		11%		-1%	
Cumulative % Increase	Cumulative increase in premiums since 2002 rates.						14%		25%		70%		68%		100%		144%		144%	

Benefits Comparison	2000 BCBS (High)	2001 Cigna HMO	2002 Cigna HMO	2003 UHC PPO	2004 UHC PPO	2005 UHC PPO	2005 UHC HDHP/HSA	2006 UHC HDHP/HSA	2007 UHC HDHP/HSA	2007 UHC HDHP/HSA
Lifetime Max	none	none	none	none	none	none	none	\$1M	\$1M	\$1M
Annual Deductible	\$0	\$0	\$0	\$0	\$0	\$0	\$4,000	\$4,000	\$6,000	\$3,000
Out-of-Pocket Max	\$0	\$0	\$0	\$0	\$0	\$0	\$4,000	\$8,000	\$10,000	\$5,000
Coinsurance	none	none	none	none	none	none	100% after deductible	90% after deductible	90% after deductible	80% after deductible
Office visits	\$10	\$20	\$20	\$10	\$20	\$20	100% after deductible	90% after deductible	90% after deductible	80% after deductible
Inpatient hospital	\$200	\$150/day (\$750 max)	\$150/day (\$750 max)	250	250	250	100% after deductible	90% after deductible	90% after deductible	80% after deductible
Outpatient surgery	\$50	\$100	\$100	\$0	\$0	\$0	100% after deductible	90% after deductible	90% after deductible	80% after deductible
Emergency	\$50	\$75	\$75	\$75	\$100	\$100	100% after deductible	90% after deductible	90% after deductible	80% after deductible
Urgent Care				\$35	\$50	\$50	100% after deductible	90% after deductible	90% after deductible	80% after deductible
Rx	\$10/\$20/\$35	\$10/\$20/\$40	\$10/\$20/\$40	\$6/\$20/\$35			combined w/ medical; 100% after deductible	\$10/\$30/\$50 after deductible	\$10/\$30/\$50 after deductible	\$10/\$30/\$50 after deductible
Bi-weekly premium (Family)	\$18	\$19	\$78	\$78	\$82	\$185	\$45	\$70	\$70	\$70

2005 gave us an 'option' that forced everyone to move from a PPO plan to an HSA plan.

### Total Family Premiums

Year	HMO/PPO	HDHP	HDHP+ max HSA contrib	Employee Contributions (HSA-adjusted)
2002	\$ 7,047.00			\$ 2,050.47
2003	\$ 8,010.72			\$ 2,050.36
2004	\$ 8,806.68			\$ 2,201.64
2005	\$ 12,007.32	\$ 7,809.88	\$ 11,809.88	\$ 4,810.00
2006		\$ 10,110.88	\$ 14,110.88	\$ 5,820.00
2007		\$ 11,664.90	\$ 17,314.90	\$ 7,470.00
2008		\$ 11,512.54	\$ 17,162.54	\$ 7,470.00

2005 Premium rise (and shift to HDHP) after high-cost claims begin in 2004

2008 Premium decline (and lower deductible) after lifetime cap reached in 2007

### Raw Data - Insurance Premiums

2002 annual premiums	2002 HMO		2002 POS	
	Total	Employee	Total	Employee
Employee Only	\$2,142.00	\$623.28	\$2,296.56	\$729.64
Employee/Spouse	\$4,862.16	\$1,414.70	\$5,212.68	\$1,655.94
Employee/Children	\$4,583.88	\$1,333.82	\$4,937.28	\$1,568.53
Family	\$7,047.00	\$2,050.47	\$7,555.32	\$2,400.24

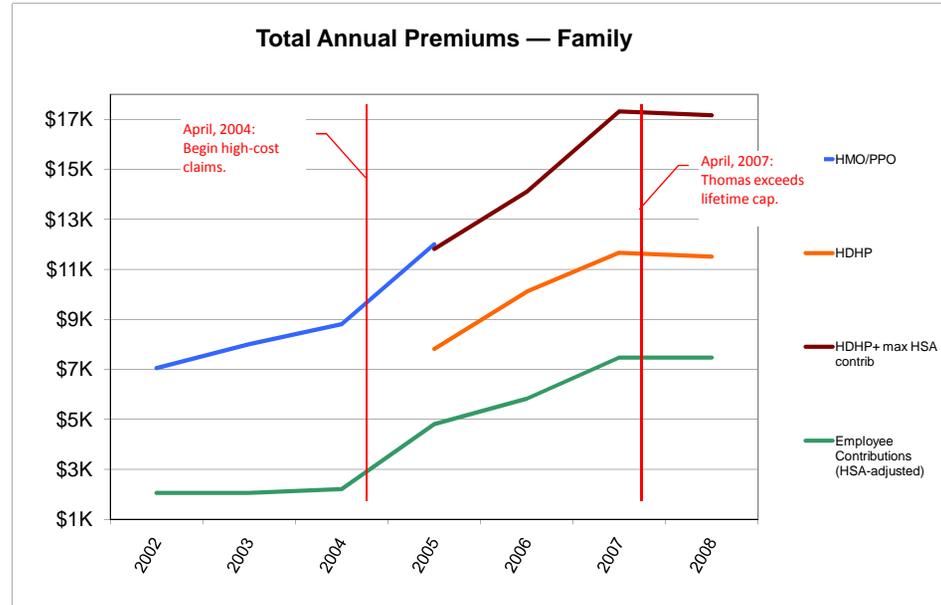
2005 premium calculations - PPO	bi-weekly		annual (biw*26)			
	premium-V	premium-E	premium-V	premium-E	total annual	
Employee Only	\$ 65.37	\$ 75.00	\$ 1,699.62	\$ -	\$ 1,950.00	\$ 3,649.62
Employee/Spouse	\$ 168.65	\$ 150.00	\$ 4,384.90	\$ -	\$ 3,900.00	\$ 8,284.90
Employee/Children	\$ 150.39	\$ 150.00	\$ 3,910.14	\$ -	\$ 3,900.00	\$ 7,810.14
Family	\$ 276.82	\$ 185.00	\$ 7,197.32	\$ -	\$ 4,810.00	\$ 12,007.32

2005 premium calculations - HSA	bi-weekly		annual (biw*26)				
	premium-V	HSA-V	premium-E	premium-V	HSA-V	premium-E	total annual
Employee Only	\$ 76.30	\$ 20.00	\$ 15.00	\$ 1,983.80	\$ 520.00	\$ 390.00	\$ 2,373.80
Employee/Spouse	\$ 177.26	\$ 40.00	\$ 30.00	\$ 4,608.76	\$ 1,040.00	\$ 780.00	\$ 5,388.76
Employee/Children	\$ 165.38	\$ 40.00	\$ 30.00	\$ 4,299.88	\$ 1,040.00	\$ 780.00	\$ 5,079.88
Family	\$ 255.38	\$ 40.00	\$ 45.00	\$ 6,639.88	\$ 1,040.00	\$ 1,170.00	\$ 7,809.88

2006 premium calculations	bi-weekly		annual (biw*26)				
	premium-V	HSA-V	premium-E	premium-V	HSA-V	premium-E	total annual
Employee Only	\$ 103.20	\$ 20.00	\$ 15.00	\$ 2,683.20	\$ 520.00	\$ 390.00	\$ 3,073.20
Employee/Spouse	\$ 228.32	\$ 40.00	\$ 40.00	\$ 5,936.32	\$ 1,040.00	\$ 1,040.00	\$ 6,976.32
Employee/Children	\$ 212.95	\$ 40.00	\$ 40.00	\$ 5,536.70	\$ 1,040.00	\$ 1,040.00	\$ 6,576.70
Family	\$ 318.88	\$ 40.00	\$ 70.00	\$ 8,290.88	\$ 1,040.00	\$ 1,820.00	\$ 10,110.88

2007 premium calculations	bi-weekly		annual (biw*26)				
	premium-V	HSA-V	premium-E	premium-V	HSA-V	premium-E	total annual
Employee Only	\$ 121.37	\$ 30.00	\$ 15.00	\$ 3,155.62	\$ 780.00	\$ 390.00	\$ 3,545.62
Employee/Spouse	\$ 269.57	\$ 60.00	\$ 40.00	\$ 7,008.82	\$ 1,560.00	\$ 1,040.00	\$ 8,048.82
Employee/Children	\$ 251.83	\$ 60.00	\$ 40.00	\$ 6,547.58	\$ 1,560.00	\$ 1,040.00	\$ 7,587.58
Family	\$ 378.65	\$ 60.00	\$ 70.00	\$ 9,844.90	\$ 1,560.00	\$ 1,820.00	\$ 11,664.90

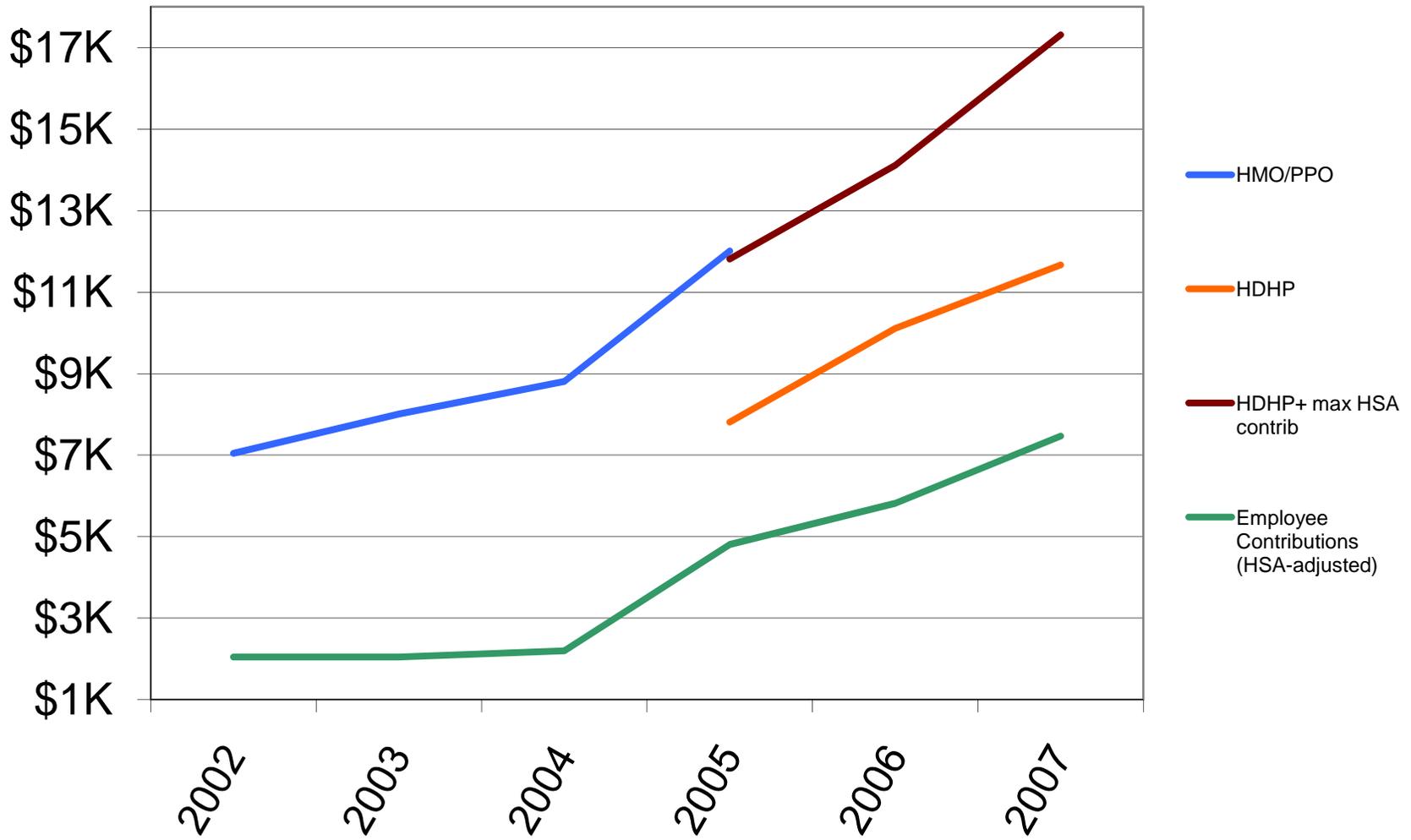
2008 premium calculations	bi-weekly		annual (biw*26)				
	premium-V	HSA-V	premium-E	premium-V	HSA-V	premium-E	total annual
Employee Only	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -
Employee/Spouse	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -
Employee/Children	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -
Family	\$ 372.79	\$ 60.00	\$ 70.00	\$ 9,692.54	\$ 1,560.00	\$ 1,820.00	\$ 11,512.54



<b>Timeline of significant events</b>	
<b>April 2000</b>	Employee #9 at Virtela (original lead engineer).
<b>August 7, 2003</b>	Thomas is born.
<b>August 10, 2003</b>	Thomas and mother discharged from hospital (spending 1 day in NICU for observation).
<b>September 2003</b>	Receive bill for <b>\$50,000</b> since NICU inside the in-network hospital is actually an "out-of-network" subcontractor.
<b>April 2004</b>	Regular high-cost medical claims as ITT/prophylactic therapy begins
<b>January 2005</b>	~35% increase in cost of insurance and shift to HDHP
<b>January 2006</b>	\$1M lifetime cap instituted
<b>December 2006</b>	Though near cap, UHC cannot give accurate figures on our proximity to cap.
<b>March 2007</b>	Spoke in favor of CO HB1355 (state bill for modified community rating for small group health insurance plans).
<b>First week of April 2007</b>	Thomas capped out of UHC plan, no longer covered by UHC.
<b>April 6, 2007</b>	Policy start date exception granted; Thomas begins Cover Colorado (state high-risk pool)
<b>April 2007</b>	Receive bill for <b>\$80,000</b> due to medical claims that exceeded the cap, but before Thomas could be covered by CoverColorado.
<b>April 2007</b>	Begin incorporation, bylaws, meeting with lawyer & CPA (re: starting consulting business)
<b>January 1, 2008</b>	CO HB1355 enacted. Insurers cannot rate small groups up due to health status or claims history.
<b>May 2008</b>	Begin payroll (insurer needs to see 3 payroll runs before starting health insurance plan)
<b>July 2008</b>	Quit job at Virtela so can work for consulting business full time for insurance benefits for family
<b>July 1, 2008</b>	Thomas (and rest of family) covered under new small group plan at RAF 1.0. CoverColorado claims were over \$900,000 (\$1M permanent cap).

<b>Other dates of interest</b>	
<b>December 2006</b>	After numerous conflicting reports about our proximity to cap (5 calls on same day = 5 wildly different answers), requested printed summary list from UHC of all claims.
<b>October 2008</b>	Finally received printed summary list from UHC of all claims through December 2006 (22 months after request).

# Total Annual Premiums — Family





## **The Impact of Lifetime Limits**

*Prepared for*

**National Hemophilia Foundation on behalf of the:**

**Raise the Cap Coalition**

**(See full list of members inside)**

**March 2009**

**For additional information, contact Michael Thompson at (646) 471-0720 or Jack Rodgers at (202) 414-1646.**

## Lifetime Caps Coalition Members

Alpha-1 Advocacy Alliance  
Alpha-1 Association  
Alpha-1 Foundation  
American Autoimmune Related Diseases Association  
American Heart Association/American Stroke Association  
American Pain Foundation  
Autism Society of America  
Baxter Bioscience  
Brain Injury Association of America  
Breast Cancer Network of Strength  
Christopher and Dana Reeve Foundation  
Committee of Ten Thousand  
Cooley's Anemia Foundation  
Crohn's and Colitis Foundation of America  
CSL Behring  
Cystic Fibrosis Foundation  
Epilepsy Foundation  
Factor Foundation of America  
Factor Health Management  
Grifols, Inc  
Hemophilia Federation of America  
Hepatitis Foundation International  
Huntington's Disease Society of America  
Immune Deficiency Foundation  
Kids With Heart National Association for Children's Heart Disorders, Inc.  
Mended Little Hearts  
National Alopecia Areata Foundation  
National Gaucher Foundation  
National Health Council  
National Hemophilia Foundation  
National Marfan Foundation  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
National Patient Advocate Foundation  
Patient Services Incorporated  
Pediatric Stroke Network, Inc.  
Pulmonary Hypertension Association  
Scleroderma Foundation  
Sjögren's Syndrome Foundation



## The Impact of Lifetime Limits

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## Executive Summary

PricewaterhouseCoopers was engaged by the National Hemophilia Foundation on behalf of a coalition of advocacy organizations representing individual chronic diseases and disorders to conduct a study of lifetime limits under employer-sponsored medical plans. These include several high-cost conditions like hemophilia, Gaucher's disease, immune deficiencies, certain cancers and others where annual costs in the hundreds of thousands of dollars or more are not unusual. Specifically, the study examines the prevalence of lifetime limits, the number of people affected by them, and the costs of increasing, or removing, lifetime limits from health plans. The findings are based on public data, surveys of major insurers, and PwC actuarial modeling.

### Prevalence of Lifetime Limits

- About 55 percent of individuals with employer provided health insurance are subject to lifetime limits, or 91 million people in 2009. The proportion of individuals with employer coverage, who have no lifetime limits increased substantially between 2000 and 2007.
- The most common lifetime limits are \$1 million or \$2 million. More than 20 percent of people covered by employer plans are subject to lifetime limits of \$1 million; another 32 percent are subject to limits of \$2 million or more.
- Employers that self-insure are more likely to have plans with lifetime limits.
- PwC estimates that in 2009 approximately 20,000 to 25,000 people are no longer covered by their employer-sponsored plans because of lifetime limits.

### Cost of Removing Lifetime Limits

- Increasing lifetime limits from \$1 million to \$5 million would increase premiums, on average, by 0.6 percent to 0.8 percent (approximately \$3 per month for typical single plan, \$8 per month for family plan).
- Increasing lifetime limits from \$2 million to \$5 million would increase premiums, on average, by 0.25 percent to 0.35 percent (less than \$2 per month for typical single plan, \$4 per month for family plan).
- Extending the limits from \$5 million to \$10 million would increase premiums on average by less than 0.1 percent.

### Illustrative Impact of Lifetime Limits in 2019

- If lifetime limits are not increased, the number of individuals who are no longer covered by their employer-sponsored plans because of lifetime limits will increase exponentially as healthcare costs continue to rise.
- According to the U.S. Department of Health and Human Services, healthcare costs per capita are projected to rise at about 6 percent annually, or about 80 percent over the next 10 years.
- At this rate of increase, PwC estimates approximately 300,000 people (0.3 percent of the people with lifetime limits) would be affected by lifetime limits in 2019 if current limits were not increased.

### Medicaid Savings from Increasing Lifetime Limits to \$10 Million

- Many individuals who lose insurance coverage because of lifetime limits fall back on government programs, primarily Medicaid.
- If lifetime limits were increased to \$10 million, PwC estimates that Medicaid programs would save more than \$1 billion in 2010.

## **I. Background**

PricewaterhouseCoopers was engaged by the National Hemophilia Foundation on behalf of a coalition of advocacy organizations representing individual chronic diseases and disorders to conduct a study of lifetime limits under employer-sponsored medical plans. Specifically, the study examines the prevalence of lifetime limits, the number of people who are affected by them, and the costs of increasing or removing lifetime limits from health plans.

Lifetime limits are provisions of many insurance plans that limit the total dollars in benefits that the insurance plan will pay out over the lifetime of an enrollee in the plan. For example, a health plan might specify that once \$1 million in benefits are paid out, the insurance plan no longer will pay for any claims for that enrollee. An individual may reach the limit in one year in the case of a catastrophic medical conditions or an individual with chronic disease may reach the limit over five years by having \$200,000 in medical expenses each year. The latter situation is associated with diseases, such as hemophilia, which have high annual treatment costs.

People who have spending that exceed health plan limits have to find other ways to pay for medical costs, which involves a combination of paying more out of pocket, finding new public or private insurance sources (often through Medicaid) and curtailing medical care. Medicaid has income and asset limits so it may take months or years to "spend down" assets and become eligible for Medicaid. Some people are able to start over with new insurance plans as a result of job changes or insurance changes initiated by their employers. Some of these individuals qualify for Medicare after being disabled for two years.

The National Hemophilia Foundation, on behalf of a coalition of advocacy organizations representing individual chronic diseases and disorders, asked PricewaterhouseCoopers to estimate the following aspects of lifetime limits:

- Prevalence of lifetime limits including number of people whose health plans include them as well as how many people are affected by the limits;
- How the lifetime limits and the number of people affected by them have changed over time;
- The cost of removing lifetime limits in terms of increases in premium costs to employers; and,
- The savings to public programs, most specifically Medicaid if lifetime limits were removed.

There is currently no uniform industry source of data on lifetime maximum benefit plans and cost impact. The PricewaterhouseCoopers findings are based on public data, surveys of major insurers, and PwC actuarial modeling. The following summarizes our sources:

- PwC researched the public domain for surveys and reports on lifetime maximum distributions and cost. The overall estimates were based on the 2007 Kaiser Foundation Annual Survey Report on Employer Health Benefits.
- PwC performed a survey of several major national insurance carriers in which information was collected on:
  - lifetime maximum cost impact;
  - reinsurance issues;
  - distribution of current participant enrollees by lifetime maximums;
  - employer processes when transferring vendors;
  - current and historic trend patterns (e.g., amount maximums changed).

PwC developed an actuarial model utilizing a large national claim database to develop estimates of the frequency with which covered individuals hit lifetime maximums and costs associated with their plans.

**II. Prevalence and Impact of Lifetime Limits**

PricewaterhouseCoopers reviewed several sources of information available on the prevalence of lifetime limits in employer-sponsored health insurance plans. Based on our marketplace experience, review of other benefit surveys and interviews of several major insurance carriers, the most common lifetime maximum limits for companies with at least 20 employees are \$1 million, \$2 million and unlimited.

The table below, which is based on the 2007 Kaiser Family Foundation employer survey, summarizes enrollment by plan type.<sup>1</sup> An estimated 22 percent of people covered by employer plans are subject to lifetime limits of \$1 million; another 32 percent are subject to limits of \$2 million or more. Research by PricewaterhouseCoopers suggests that most lifetime limits that are under \$2 million are set at exactly \$1 million. A majority plans with limits of \$2 million or more are set at \$2 million.

<b>Prevalence of Lifetime Limits</b>	
<b>Lifetime Limit</b>	<b>% of Individuals Enrolled</b>
Less than \$1 million	1%
\$1 million - less than \$2 million	22%
\$2 million or greater	32%
Unlimited	45%

Source: Kaiser Family Foundation, 2007

Self-insured firms are more likely to have limits than firms that buy commercial insurance. Individual firms are not able to spread the costs of high-cost cases across as many lives as commercial insurers do. In terms of the number of people affected, PwC estimates that approximately 91 million people covered by employer plans are subject to lifetime limits. PwC estimates in 2009 that approximately 20,000 to 25,000 individuals reach their lifetime limits.

The number of people who exhaust lifetime limits will increase dramatically unless the limits are increased to keep up with the growth in medical costs. For example, by the year 2019, medical costs will be 80 percent higher than 2009, assuming healthcare costs increase 6 percent annually. Unless lifetime limits are increased, the number of individuals who will lose employer-provided benefits because of lifetime limits will increase exponentially. Assuming no change in the current lifetime limits take place, PwC estimates that approximately 300,000 people (0.3 percent of individuals with lifetime limits) will reach their lifetime limits in 2019.

**III. Costs of Increasing Lifetime Limits**

When lifetime limits are increased, the total health plan costs will increase based on an increase in the claims and reinsurance cost components. The administrative component will have a minimal increase. The reinsurance cost component will increase to reflect the greater financial assumed by the reinsurer as a result of any increase to the lifetime limit. Additionally, claims will increase as plan costs for ongoing claimants that are below the stoploss level increase.

<sup>1</sup> *Employer Health Benefits, 2007 Annual Survey*, Kaiser Family Foundation and Health Research and Education Trust, Washington, DC, 2007; available at <http://www.kff.org/insurance/7672>

PwC estimates that for 2009 the average monthly health premiums are approximately \$420 for single coverage and \$1,125 for family coverage.<sup>2</sup> Based on the size of an insurance carrier's book of business and the low overall frequency with which individuals reach lifetime limits, the cost of increasing the limits would be low (less than 1 percent of costs). As shown in the table below, PwC estimates that increasing lifetime limits from \$1 million to \$5 million would increase premiums by approximately 0.6 percent to 0.8 percent, or about \$3 per month for single coverage or \$8 for family coverage. The costs of increasing a \$2 million limit to \$5 million would increase costs by an estimated 0.25 percent to 0.35 percent, about \$1.50 for single coverage and \$3.50 for family coverage. Finally, increasing limits from \$5 million to \$10 million would increase cost by less than 0.1 percent, less than \$1 per month for either single or family coverage. Based on the current distribution of plans and their lifetime limits, we would estimate that the aggregate composite cost increase for all companies with lifetime limits would be 0.4 percent to 0.6 percent.

<b>Premiums to Increase or Remove Lifetime Limits</b>		
<b>Lifetime Limit Change</b>	<b>% change</b>	<b>Monthly premium change</b>
\$1 million to \$5 million	0.6 - 0.8%	\$3 (single)/\$8 (family)
\$2 million to \$5 million	0.25 - 0.35%	\$1.50 (single)/\$3.50 (family)
\$5 million to \$10 million	less than 0.1%	less than \$1 for single or family

Source: PricewaterhouseCoopers estimates

While the above cost increments represent average cost increases, the increases could be greater for any specific smaller self-insured or insured experience-rated employer who has ongoing high dollar chronic claimants in their covered population.

#### **IV. Changes in Lifetime Limits, 1988-2007**

All aspects of lifetime limits have changed during the past two decades. Not only have lifetime limits been increased as medical costs have risen but also the number of subject to lifetime limits has declined. The table below provides information from 1988 to 2007 showing that the percentage of people subject to lifetime limits in employer-sponsored plans has fallen from 79 percent in 1988 to 55 percent in 2007. During the same period the number of people subject to limits less than \$1 million has decreased from 34 percent to about 1 percent.

<sup>2</sup> The 2007 Kaiser survey indicated average monthly premiums of approximately \$373 for single and \$1,009 for family coverage. PwC added two years of medical trend (approximately 6% per year) to the 2007 Kaiser numbers.

<b>Prevalence of Lifetime Limits, 1988-2007</b>						
	<b>2007</b>	<b>2004</b>	<b>2002</b>	<b>2000</b>	<b>1990</b>	<b>1988</b>
Percent unlimited	45%	49%	33%	22%	22%	21%
Percent under \$1 million	1%	1%	4%	6%	22%	34%
Percent \$1 million or more	54%	50%	63%	72%	56%	44%
Value of \$1 million (2007 dollars)	\$1.0	\$1.2	\$1.3	\$1.6	\$2.8	\$3.6

Source: PricewaterhouseCoopers calculations based on data from employer surveys, 1988-2007

However, while lifetime limits have increased over the past two decades, the increases have not kept pace with increases in medical costs in all instances. If a 1988 lifetime limit of \$1 million is adjusted for the growth in healthcare costs (as shown in the last row of the table), the 2007 equivalent lifetime limit would be \$3.6 million. If we can consider that 65 percent had a lifetime limit of \$1 million or more in 1988, there would need to be at least 65 percent of the populations today with a lifetime limit of \$3.6 million or more for there to be no change. However, where lifetime limits exist today, only a low percentage of those limits are greater than \$2 million. Consequently, the data suggests that at the high end of the range, lifetime limits may actually affect more people today than in 1988.

Other data (not shown in the table) suggests that the percentage of people with lifetime limits below \$1 million (in 2007 dollars), has fallen over the past two decades. For example, in 1990, 7 percent of people with employer coverage were subject to lifetime limits less than \$250,000, which is equivalent to \$700,000 in 2007 dollars as compared to only 1 percent who were below the higher \$1,000,000 limit in 2007. It would appear that the percentage of people subject to particularly low lifetime limits has declined over the two decades.

The historical data on lifetime limits does not provide a clear answer as to the changes in impact of the limits over time. Clearly fewer people are subject to lifetime limits today as compared with two decades ago. However, a lifetime limit of \$1 million, which was the most common limit in 1988, is still quite common today.

**V. Savings to Medicaid from Increasing Lifetime Limits**

People whose spending exceeds a lifetime limit under their current insurance plan will seek other sources of coverage. Those who are financially well off may be able to pay for their care without assistance but most people will turn to other public and private sources. The most common source of care for those who meet income eligibility requirements is Medicaid.

For example, data from the U.S. Centers for Disease Control and Prevention (CDC) show that people with severe hemophilia are much more likely to have Medicaid coverage than is typical in the general U.S. population. The table below shows that about 14 percent of people in the U.S. have Medicaid coverage in a typical month. On average, 19 percent of people with hemophilia list Medicaid as their source of coverage. People with severe hemophilia are even more likely to have Medicaid coverage-- 29 percent compared to 18 percent of people with mild hemophilia.

Medicaid Coverage	
General US Population	14%
People with Hemophilia	
Mild	18%
Severe	29%

Source: PricewaterhouseCoopers calculations based on data from the CDC (<http://www2a.cdc.gov/ncbddd/htcweb/>)

PwC estimated the impact of lifetime limits on the total spending under Medicaid based on the lifetime limits in place today. Based on our finding that increasing lifetime limits to \$10 million would increase premiums by 0.5 percent, we estimate that spending within the lifetime limits in 2010 would be about \$2.1 billion. Using the conservative assumption that Medicaid, absent the increase in the limits, would replace 50 percent of those benefits, Medicaid savings from increasing the lifetime limits would be more than \$1 billion in 2010 dollars. Moreover, the amount would grow over time as medical costs rise. We estimate that Medicaid would save more than \$11 billion over the next 10 years.<sup>3</sup>

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<sup>3</sup> This estimate does not include spending above lifetime limits in firms with fewer than 20 employees. Small firms would likely be exempted from legislation to remove limits.

## **Raise the Cap Coalition**

The Honorable Henry Waxman  
Chairman  
House Committee on Energy and Commerce  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Joe Barton  
Ranking Member  
House Committee on Energy and Commerce  
2322-A Rayburn House Office Building  
Washington, DC 20515

September 16, 2009

RE: Provision to Eliminate Lifetime Limits on Private Insurance in HR 3200

Dear Chairman Waxman and Ranking Member Barton:

On behalf of the undersigned organizations and millions of Americans with chronic diseases and conditions, thank you for your efforts to reform our healthcare system so that there will be adequate, affordable health care for all Americans. We strongly support the insurance market reforms included in HR 3200, especially the elimination of lifetime and annual limits on benefits. However, we are concerned about the delayed implementation of this provision for existing plans, and urge you to expedite its implementation.

Lifetime limits on private insurance pose a considerable problem for individuals with chronic diseases and conditions. Many private insurers continue to set lifetime caps on health coverage at \$2-\$3 million; no additional coverage is provided once these limits are reached. A person with a high cost chronic disease or condition could exhaust their benefits in as few as 5 years, or even in one or two in the case of a medical crisis. Increasing or eliminating lifetime caps would result in savings for state and federal governments, since individuals with high medical costs would be able to maintain their private insurance rather than be forced onto Medicaid. Independent analysis by PricewaterhouseCoopers found that more than \$11 billion over ten years would be saved by raising lifetime caps.

HR 3200 eliminates lifetime caps in "qualified health benefit plans" offered through the Exchange or through new employer-based plans as of 2013; existing group plans are exempt from this requirement until 2018. Since most people with chronic diseases and conditions have employer-sponsored insurance plans, as it is often prohibitively expensive for them to secure individual market insurance, these people could be subject to lifetime limits for an additional 9 years. This is simply too long.

We respectfully request that you amend HR 3200 to implement the elimination of lifetime caps in the next plan year after the law is enacted, similar to the enactment of the language prohibiting insurance policy rescissions. Rescissions are similar to lifetime caps in that both are insurance company practices which penalize people who submit high-cost claims. Rescissions may have a more immediate impact since they occur following the submission of claims, but the end result is the same: a person with a serious medical condition loses insurance coverage. In both cases, people are forced to make difficult decisions about their jobs, residences and even family life to secure new coverage.

Alternatively, we propose an interim policy for lifetime caps following the path in HR 1085, the bi-partisan Health Insurance Coverage Protection Act. HR 1085 sets a minimum lifetime cap for

all plans at \$5 million in plan years one and two, and \$10 million for plan years three and four, with an inflationary update for subsequent plans years. The minimum lifetime cap could be in place until caps are eliminated in 2013 and 2018, as the bill currently sets forth. This approach of implementing an interim policy is similar to the approach that the Education and Labor Committee took with respect to pre-existing condition exclusions.

Individuals with chronic diseases and disorders must not be impeded in accessing necessary health care nor should they be impoverished with unreasonable lifetime limits on benefits. We respectfully ask that you implement the elimination of lifetime caps in the next plan year following enactment of the law, or at least provide an interim policy to phase-in the elimination of caps more quickly.

Sincerely,

Alpha-1 Association  
Alpha-1 Foundation  
American Cancer Society Cancer Action Network  
American Heart Association/American Stroke Association  
Arthritis Foundation  
Autism Society  
Baxter Healthcare Corporation  
Brain Injury Association of America  
Breast Cancer Network of Strength  
Christopher and Dana Reeve Foundation  
Committee of Ten Thousand  
Cooley's Anemia Foundation  
Crohn's and Colitis Foundation of America  
CSL Behring  
GBS/CIDP Foundation International  
Grifols  
Hemophilia Federation of America  
Huntington's Disease Society of America

Immune Deficiency Foundation  
Interstitial Cystitis Association  
Kids With Heart National Association for Children's Heart Disorders, Inc  
National Family Caregivers Association  
National Gaucher Foundation  
National Health Council  
National Hemophilia Foundation  
National Marfan Foundation  
National MS Society  
National Organization for Rare Disorders  
National Patient Advocate Foundation  
Patient Services Incorporated  
Pediatric Stroke Network  
Plasma Protein Therapeutics Association  
Platelet Disorder Support Association  
Prevent Blindness America  
Pulmonary Hypertension Association  
Scleroderma Foundation  
Sjögren's Syndrome Foundation