What Health Care Reform Means to HomePEN Consumers
Frances Culp, M.A.

In March 2010, health care reform became a reality when President Obama signed two bills into law: the Patient Protection and Affordable Care Act and the Health Care and Education Reconciliation Act of 2010. Together, these bills represent the most significant changes to the health care system since Medicare and Medicaid were established in 1965.

The American system of health care is greatly varied, with its mixture of public and private insurance providers and ways in which people connect to and access health insurance coverage. Insured individuals gain coverage through governmental programs (e.g., Medicare) or rely on the private system through their employer or individual coverage. These bills do not change this; the variability remains. Instead, these bills increase access to health care for many of the approximately 46 million uninsured Americans by closing a number of gaps in the system. By 2019, it is estimated that an additional 32 million Americans will have health insurance (92 percent of the population).

The Changes
It is the responsibility of the federal government to interpret the policies and provide exact regulations to the players involved (states, insurance companies, businesses, etc.). This article will explore what we know thus far, with a focus on changes most relevant to Oley members presented in a timeline. It is not meant to be comprehensive; its scope does not include all of the regulatory changes to employers and health care providers.

FDA Seeks to Reduce Pump Risks
This spring the Food and Drug Administration (FDA) launched an initiative to address safety problems associated with external infusion pumps. Acknowledging the important role that infusion pumps play in many people's lives, Jeffrey Shuren, MD, director of the FDA's Center for Devices and Radiological Health, stated that pump “failures have significant implications.” “It is time,” he continued, “for a more comprehensive approach than we've taken to date.”

In the past five years, the FDA has received more than 56,000 reports of adverse events associated with the use of infusion pumps (this includes use in hospitals, other clinical settings, and at home). Between 2005 and 2008, eighty-seven infusion pump recalls were conducted to address safety concerns. The most common types of problems reported have been related to software defects, including failures of built-in alarms; user interface issues, such as ambiguous
Health Care Reform, from pg. 1

90 Days after Enactment (July 2010):
1. National High-Risk Health Insurance Pool to be established. Health and Human Services (HHS) has communicated with all states their responsibility to have a functioning high-risk health insurance pool. The states may accept federal funding to start a new pool, build upon an existing pool, or decline funding, allowing the federal government to operate the pool. Most states have some version of a high-risk pool that accepts individuals who have been denied private health insurance coverage due to a pre-existing condition. Not all are well functioning; many are not accepting new enrollees. The new programs are meant to be an effective alternative for those who are shut out of the private insurance market. Subsidies will be provided to offset the cost of the premiums; however, enrollees must have been uninsured for at least six months before they can join the new pools. The benefit requirements have yet to be established. In 2014, when private insurers are no longer able to deny individuals who are considered high-risk, these high-risk pools will be disbanded.

2. New consumer Web site. HHS is developing a Web site that will begin on a limited basis in July; eventually it will include information about health insurance options available in each state, premium prices, and Medicaid eligibility, as well as other information.

6 Months after Enactment (September 23, 2010):
These new laws represent changes to some of the more odious practices of the private health insurance market. For existing plans, some of these changes (such as the provision for dependent health insurance, number 4 below) will not take effect for the consumer until the current plan year expires and the new plan year begins. The laws:

1. Bar insurers from denying people coverage when they get sick. Insurers may not retroactively cancel approved individual health insurance policies after the policyholder gets sick and files large medical claims (known as rescission) unless the insurer can show that the person lied or knowingly omitted information on his or her application, in which case the insurer can still cancel the policy.
2. Bar insurers from denying coverage to children (up to 18) due to pre-existing conditions. Adults with pre-existing conditions do not receive the same protection until 2014.
3. Bar insurers from imposing lifetime caps on coverage and regulate annual limits. Currently, some plans impose lifetime limits and some have annual limits, both of which allow insurers to stop paying claims at a certain point.
4. Require insurers to allow young adults to stay on parents’ policies until their 26th birthday. This change will allow dependents to remain enrolled through, or to rejoin, a parental insurance policy as a dependent up to age 26, easing young adults through this transition time. Many young adults, especially those with health problems, struggle to find health insurance and quite a few end up uninsured for some period of time before they can find a job that offers health insurance. Parents will also have an opportunity to rejoin a plan or join a different plan that offers better dependent coverage. In a show of good faith, a number of large insurers, including Blue Cross/Blue Shield, Aetna and others, have agreed to start this coverage for young adult dependents before the required deadline (September 23, 2010).
5. Establish appeal mechanisms, including appeals to independent review organizations, for all plans, including large group plans. (This may not apply to existing or “grandfathered” plans, which will be exempt from certain consumer protections.)

Within 1 Year:
1. The laws provide for a $250 rebate to Medicare prescription drug plan beneficiaries in the Part D “Doughnut Hole.” Health care reform will incrementally close this “Doughnut Hole” by reducing beneficiary responsibility for the gap from 100 percent to 25 percent by 2018. The first step in this process provides a $250 rebate to Medicare beneficiaries who reach the Part D coverage gap.

2011:
1. The laws provide for a 50 percent discount on brand-name drugs for Medicare prescription drug plan beneficiaries in the Part D “Doughnut Hole.” The next step in closing the “Doughnut Hole."

2014:
1. Health benefit exchanges. Each state must create a health benefit exchange operated by
The Joys of Tube Feeding
(adapted with permission from an entry on the Oley Inspire Forum, www.inspire.com/groups/oley-foundation)

We all have difficulties and complications with our G- and J-tubes, but I thought it would be neat to create a list of why it's totally cool to have a G-tube and all the ways it is a bonus in my life. So here goes:

1. I never have to worry about having food in my teeth! No fear of the embarrassing comment, “By the way, you’ve had a piece of spinach on your tooth for the last half hour.”
2. When on a canned diet, there’s no grocery shopping, food preparation, refrigeration, microwaves, or ovens involved! No mess, no dishes. I just pop a can lid.
3. More time! My day is not spent eating, buying food, or waiting in line.
4. Although I believe I will be better off on real food, there’s no worry about balanced nutrition, hidden calories, excess sodium or sugar, or unhealthy fat. It’s all balanced right there in my can. Just syringe and go.
5. It doesn’t matter what the food tastes like. I can completely bypass the taste buds and gag reflex.
6. I can keep hydrated without a fuss if I’m diligent. Eight to ten glasses of water a day? No prob! I just squirt it through my tube.
7. I have the most unique body piercing ever. Others may have rings, studs, or spikes. I’ve got a piercing that looks like a beach ball valve. Besides, regular piercing is for wimps. I’ve got a piercing as thick as a pencil right through muscle and an organ wall. So I win the toughness contest.
8. If the tube is ever removed, I will have two belly buttons. How adorable is that? Not to mention unique. Marilyn Monroe had six toes, and I’m pretty sure two belly buttons is more rare than that. I’m special. As a kid, I was always distressed that I didn’t have freckles. But I think two belly buttons makes up for that.
9. Carrying the boxes of formula is good exercise, and especially great for the biceps. Tell me you get a calorie-burning workout lifting a hamburger.
10. I am a dog’s best friend. The formula smells like gourmet canned dog food apparently, and dogs sit in an adoring circle waiting for me to throw my cans into the recycling bin so they can dash over and lick off any stray drops. Feels nice to be such a source of happiness.
11. I have the perfect defense against intruders. If any robber stands in my doorway with a pistol, I will aim the end of my tube at him, uncap it, and vent! He will immediately leave and I will be a hero. It’s my superpower.
12. Packing for lunch is incredibly easy. What should you bring for lunch? Can, can, and can. Mission accomplished.
13. When empty, the boxes the cans come in are perfect for sorting files into.
14. Never again will I have to suffer through anyone’s burnt, bland, or bad cooking.
15. No worry about overpriced food at restaurants, airports, or tourist destinations.
16. If I could just attach a squeaker or flashing light to my button, I could entertain little kids for hours.
17. And finally, and seriously, it keeps me alive. Best bonus of all, I would say.

— Christine, aka “Jackrabbit”
Bright Idea

Mattress Genie

I have struggled with acid reflux and gastroparesis for a long time. These problems can be exacerbated at night if I lie flat. I have tried doubling and tripling pillows and a wedge pillow, but either the pillows would flatten too much or I would slide down on the wedge, and during the night I would wake up nauseous and possibly vomiting, or my acid reflux would be bothering me. It got to where I was sleeping almost straight up on the couch. I missed being able to lie down in a bed, and sleeping that way on the couch was uncomfortable.

I thought about buying an adjustable bed over the Internet. In the course of my search I came across the Mattress Genie Adjustable Bed Wedge made by Contour Products. The Genie enables me to adjust the head of my bed by up to 40 degrees. I decided to invest in it as the price (about $100 dollars for wedge to fit a twin-sized bed) was much cheaper than the price of an adjustable bed and I wouldn’t have to find the space for a new bed.

The Genie comes with a controller that directs a pump to inflate a wedge that goes underneath the front end of the mattress. When I fill up the wedge to its largest size, I can sleep on my bed again. To sleep in the bed is a simple pleasure, but one that I am grateful for and had missed. The pump is somewhat loud when I am inflating the wedge, but it is only a temporary noise.

I have had the Genie for six months or more, and have not had any problems with it. I would recommend it to anyone else who has acid reflux problems, gastroparesis, or any other condition where you would benefit from having your head elevated at night.

—Bobbiejo Winfrey
tombeedesnues@yahoo.com

Editors Note: The Mattress Genie is available online at www.contourliving.com or by calling (800) 950-0230, Ext. 100. First-time customers can get a 5% discount by using the coupon code “newsletter.”

Have Your Questions Answered

Discuss your situation, explore options, and enjoy the fellowship of someone who can relate to your situation. All of this is available, free of charge, through Oley’s peer-to-peer phone lines program.

The following lines will be staffed by seasoned consumers or caregivers, willing to share their experiences.

• (888) 610-3008 will be devoted to HPN (intravenously infused nutrition).
• (888) 650-3290 will be devoted to HEN (tube feeding).
• (877) 479-9666 will be devoted to HPEN consumers in their teens and twenties.

We hope you’ll use this opportunity to improve your quality of life.

As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.
In Memory of Robin Lang

Robin Lang, long-time Oley volunteer and friend to many, passed away on April 15 in Portland, Maine, with her family at her side. Those who knew Robin will easily recall her quick smile and welcoming hugs. She took new Oley members under her wing and made them feel special. She shared her stories and experiences with everyone, and was the life of every gathering.

Robin was a volunteer for the Lifeline Foundation (Lee and Marshall Koonin’s organization), then, when the Lifeline Foundation and Oley merged, she became an Oley Regional Coordinator. For twenty-five years she shared support, wisdom, and friendship with hundreds of HPEN consumers. Robin played “Peaches the Clown” at early Oley gatherings and began the Sunshine Group, which provided cards and letters to Oley members who were in the hospital or going through a tough time. She and Barb Klingler initiated a travel scholarship to which Oley conference attendees donated; the money collected was pooled to help an HPEN consumer attend the next year’s conference.

In 2000, Robin co-chaired the Oley conference in Boston, which was a great success. She was the recipient of the Oley Foundation Lifeline Letter Award, the Celebration of Life Award, and the Lenore Heaphey Award for Grassroots Efforts. She spoke at many clinical conferences, teaching clinicians what it’s like to really live on HPN and telling them about the services Oley offers consumers. She wrote articles for the Lifeline Letter and she staffed the toll-free phone lines in an effort to share experiences and better the lives of those who followed in her footsteps. In short, Robin did whatever you asked her to do, and then some, never asking for anything in return. That was the beauty of knowing and working with Robin.

Sing, dance, rest in peace, Robin. We miss you.
Too Much to Carry?

We have heard that some airlines will waive the fee for checked baggage if the baggage contains medical supplies. If the airline you have chosen will not — and it may be worth inquiring before you finalize your ticket purchase — there are alternatives to checking those bags.

Shipping medical supplies or other necessities to your destination before you leave on a trip may be cheaper than paying the airlines for checked baggage — and it will make it easier for you in the airport. The old stand-bys for shipping include Federal Express, UPS, and the U.S. Postal Service. Depending on your destination, you may be able to ship supplies by bus, as well.

Further, as more airlines are charging for baggage, more companies are emerging to provide alternatives. Companies like Luggage Forward, First Luggage, and Direct Baggage (based in the U.K.) will pick up your baggage at your home and deliver it to your destination. The least expensive alternative we’ve found so far is the “economy” option through Luggage Free, which advertises “50 pounds for $50.” They ship medical supplies domestically; inquire about rules for international travel. Some airlines offer services similar to those offered by Luggage Free.

Alternative Shipping Options

We’ve compiled this list of companies by searching the Internet; it is by no means exhaustive. Be sure to research your options with your airline, check for updates online, or consult with a travel agent. Oley has no experience with any of these carriers, and therefore cannot vouch for their reliability. If you’ve found other reliable, reasonably priced ways to ship your medical supplies, we’d love to hear about them. Send your tips to Lisa Metzger at metzgel@mail.amc.edu, or call her at (800) 776-OLEY.

Direct Baggage www.directbaggage.com (intern’l # only)
First Luggage www.firstluggage.com (800) 224-5781
Luggage Ahead www.luggageahead.com (888) 395-4410
Luggage Concierge www.luggageconcierge.com (800) 288-9818
Luggage Express www.luggageexpress.com (866) 744-7224
Luggage Forward www.luggageforward.com (866) 416-7447
Luggage Free www.luggagefreeeconomy.com (800) 361-6871
Sports Express www.sportsexpress.com (800) 357-4174
The Luggage Club www.theluggageclub.com (877) 231-5131

What Oley Means to You

Your personal stories keep us going and help us move in the right direction with our programs. They are also so wonderful to share — with other members, in the newsletter, with clinicians and potential sponsors. At the annual conference we will be inviting attendees to share their stories on video for a DVD about the Oley Foundation. Please consider sending us a short recording of your personal story, too, and tell us how Oley has impacted your life. Or if you’d prefer, put your story on paper and send it to us. Or add to the thread called “Thank God for Oley!” on the Oley forum (http://www.inspire.com/groups/oley-foundation/discussion/thank-god-for-the-oley-foundation). We’d love to hear from you!
Book Provides Valuable Tools:
A Review of *Know Your Rights*

Ann DeBarbieri

Those of us with chronic illness, or primary caregivers for children or others with chronic illnesses, learn early on how important it is to strongly advocate for ourselves or our loved ones. We know what it is like to hit the brick wall of being told something can't or won't be done. Wouldn't it be great to have a single resource that would tell us what the law requires of physicians, employers, schools, and others? *Know Your Rights: A Handbook for Patients with Chronic Illness,* third edition, by Jennifer C. Jaff, is such a resource.

Jaff is an attorney and the founder of Advocacy for Patients with Chronic Illness, Inc., a not-for-profit organization dedicated to providing free legal information, advice, and advocacy services to patients with chronic diseases. Her advocacy efforts grew out of her own experience in living with a chronic illness.

The handbook focuses on many areas of concern. These include how to obtain your own medical records; get and keep health insurance; appeal denial of coverage by your insurance carrier; address a denial or discontinuation of coverage from a private disability insurance company; and apply for Social Security Disability and appeal a denial of coverage. The book also addresses discrimination in employment and public accommodations; Family and Medical Leave Act issues; and education-related laws for grade school through graduate school students.

This book is not a light read. It is not something most people will want to read cover to cover in one sitting. However, it is an excellent starting point in learning about the laws that apply to these topics. In spite of the complexity of the issues, Jaff uses clear language to describe the laws. The main body of the book is focused on federal laws and how the courts have interpreted them. Armed with this information, the reader can then refer to the extensive appendices, which provide information on relevant state laws on some of the topics (and which actually make up more than half the book).

Of even more value, however, are the sample letters, forms, and appeal narratives that are included in the appendices. These are very practical examples of what should be included and the level of detail necessary to be successful. Finally, throughout the book Jaff provides references to various Web sites that are available for further information.

It is clear that in writing this book Jaff has drawn on a wealth of experience in advocating for herself and others with chronic illnesses. She has succeeded in creating a valuable tool that can be of use to anyone facing the issues covered in the book. Proceeds from the sale of the book help to fund the work of Advocacy for Patients with Chronic Illness, making purchase of the book even more worthwhile.

*This book is available for $30 plus shipping ($3.50 for one book; discounts for multiple copies). Order online at www.advocacyforpatients.org or send payment with order to Advocacy for Patients with Chronic Illness, 18 Timberline Dr., Farmington, CT 06032.*
Nutrition and You

How Sweet It Is—Sometimes Too Sweet!

Sugar makes our food tasty and provides energy in the form of calories. It is the “simple” form of carbohydrate that is found in fruits (as fructose), fruit juices, and table sugar, for example. The average person in the United States consumes about 22 teaspoons of sugar per day — nearly 360 calories from sugar alone and more than 10 teaspoons above the upper daily consumption limit recommended by the Food Guide Pyramid.

The unhealthy links between excessive oral sugar consumption and dental caries and childhood obesity are well known. But did you know that some of the unpleasant gastrointestinal (GI) side effects that we may experience are related to how we digest and absorb excessive amounts of sugar? Our taste buds may welcome the sweetness, but our guts don’t like sugar — at least not in very high quantities all at once!

Where’s the sugar?

Sugars are naturally present in some foods; fructose in fruit and lactose in milk are sugars. Most of the sugars in our diets, however, are added in preparation and processing. These include white and brown sugar, corn syrup, corn syrup solids, malt syrup, maple syrup, fructose sweetener, and liquid fructose. More than one-third of the added sugar in our diets comes from sugar-sweetened beverages (soft drinks, fruit drinks, fruit punch, sports drinks, energy and vitamin water, sweetened ice tea, cordials, and lemonade).

High fructose corn syrup is added intentionally during food processing to increase the palatability of beverages, cereal, baked goods, dairy products, and confections. Ironically, sugar consumption has risen dramatically over the last few decades as health-conscious Americans choose low fat foods and food manufacturers respond by adding inexpensive high fructose corn syrup and other sweeteners to many products.

Food manufacturers also add sugar alcohols, including sorbitol, erythritol, mannitol, and xylitol, to sweeten many dietetic products, such as sugar-free gum, mints, and candies. These sugars are also added to non-food items such as toothpastes, cough syrup, and other liquid medications. Because they are low-digestible carbohydrates, sugar alcohols provide sweetness while decreasing total calories.

Artificial sweeteners or sugar substitutes may also be used instead of sugar. These substances are chemicals or natural compounds that are many times sweeter than table sugar. Consequently we can use much smaller amounts of artificial sweeteners to get the taste we want without added calories or unpleasant GI side effects. Saccharin, used in Sweet N’ Low, is 300 times sweeter than sugar; aspartame, used in NutraSweet and Equal, is 200 times sweeter than sugar; and sucralose, better known as Splenda, is nearly 600 times sweeter than sugar. The National Cancer Institute (www.cancer.gov) reports that artificial sweeteners are safe and moderate use does not increase cancer risk.

What happens in the gut?

Low-digestible carbohydrates such as sugar alcohols are not completely digested or absorbed in the small intestine and are partially fermented in the large intestine, producing gas. In healthy intestines, carbohydrate malabsorption can occur after consumption of small amounts of sugar alcohol, causing abdominal cramps, bloating, gas, and diarrhea. The same symptoms may occur when significant amounts of fructose and large amounts of sucrose are consumed; they may exceed the absorptive capacity of the small intestine.

Intolerance may result from a high osmotic load, rapid intestinal transit, impaired absorption, and/or bacterial overgrowth in the distal small bowel. (High osmotic load refers to unabsorbable watersoluble solutes that remain in the bowel and retain water.) Unpleasant side effects may be worse in individuals who have had gastric surgery or a diagnosis of pancreatic insufficiency, inflammatory bowel disease, celiac sprue, short bowel syndrome, and certain inborn errors of metabolism.

Finding a Balance

How do we satisfy taste and minimize unwanted GI side effects? It’s a balancing act. Remember that sugar primarily adds extra calories to your diet and foods high in added sugar are generally low in nutritional value.

If you do not eat a lot of sugar and do not experience unpleasant side effects, enjoy! If you wish to decrease the amount of sugar in your diet, become an avid food label reader. If the amount of sugar in grams per serving exceeds 50 percent of the total quantity of carbohydrates in grams per serving, the product has too much sugar and should be avoided.

If you crave sweetness, choose natural sources of sugar, such as fruits, vegetables, and dairy products, and benefit from the vitamins, minerals, and fiber that come along with it. Make a smoothie by blending fresh fruit (such as strawberries and banana) with ice cubes. Avoid consuming large amounts of foods with high fructose corn syrup or sugar alcohols.

You can flavor beverages with fresh berries, peaches, limes, lemons, or oranges. Tomato and vegetable juices are healthy options to replace fruit juices if you can get away with the high sodium content. Consume sports drinks sparingly as long as you are not an endurance athlete or participating in a marathon. Select water as a healthy alternative to sugar-sweetened beverages unless you have been instructed to drink oral rehydration solutions. Use moderate amounts of artificial sweeteners. Finally, if you absolutely must have sugar, take a small taste or sip of your favorite sweet and savor it for a long while.

This column has been compiled and reviewed by Marion Winkler, PhD, RD, CNSC; Carol Iretón Jones, PhD, RD; Laura Matarese, PhD, RD, LD, FADA, CNSD; and Cheryl Thompson, PhD, RD, CNSD.
Dear Friend of Oley,

On behalf of the 10,000 members we support, we encourage you to make a gift to the Oley Foundation.

Your generosity brings expertise to consumers in need, hope to families in times of trouble, and connection to people in isolation. Ultimately, it means the difference between just surviving and truly living life to its fullest.

As member and parent Jacquelyn Katon affirms, your support has a huge impact:

*When people ask me how I do it — prepare the daily infusions, formula and meds, go through the ups and downs of infections and hospitalizations, stay on top of the doctors' appointments, testing, etc. … in addition to the regular challenges of raising two active, imaginative boys — I tell them I plan the best I can and then just go with the flow of the adventure.*

*It hasn't always been like this.*

*When we first brought Rafael home from the hospital, we were overwhelmed by the responsibilities involved in his daily care, as well as paralyzed by fear of the unknown future. We felt very alone in our situation. We were desperate for information — someone who could share their experiences and tell us how to help keep Rafael safe, and what to expect down the road.*

*Then, one day our home health care company sent us a copy of the Oley newsletter. We connected with the foundation, and our lives haven’t been the same since. Over the years we’ve made many friends and learned much about caring for Rafael. He’s grown to be a happy, mostly healthy six-year-old.*

*This isn’t to say that things are always easy, or that the journey holds any guarantees. But knowing we have somewhere to turn for information and support has made a world of difference to our family.*

Please consider what Oley means to you and your loved ones, and make a gift today.

For your convenience an envelope is enclosed in this newsletter. Or, if you prefer, you may contribute online at www.oley.org.

Gratefully yours,

Joan Bishop
Executive Director

Rafael and his brother, Aron
either a governmental agency or a nonprofit organization, through which individuals or small businesses can purchase health insurance. If a state has not taken adequate steps toward creating an exchange by January 1, 2013, the federal government will establish the exchange for that state. States may create one exchange for individuals and one exchange for small businesses, or combine the two. Citizens, legal immigrants, and employers with one hundred or fewer employees may purchase coverage through the exchange. Larger employers may purchase coverage through exchanges by 2017. Insurance plans in the exchanges will be required to offer benefits that meet a minimum set of standards (as yet to be defined). Insurers will offer four levels of coverage that vary by premiums, out-of-pocket costs, and benefits beyond the minimum requirements, plus a catastrophic plan.

2. Requirement begins for most people to have health insurance. Individuals who do not obtain coverage will be required to pay an annual financial penalty. Penalties will be phased in between 2014 and 2016. The penalty for individuals will start at $95, or up to 1 percent of household income, whichever is greater, and rise to $695, or 2.5 percent of household income (up to a maximum of $2,085 per family) by 2016.

3. Premium tax credits must be provided for families and individuals earning between 133 percent and 400 percent Federal Poverty Level (FPL) to purchase health insurance. These tax credits will be offered on a sliding-scale basis and will limit the cost of the insurance premiums to between 2 percent of income for people with incomes up to 133 percent of FPL, and 9 percent of income for people with incomes between 300 and 400 percent of FPL. Cost-sharing subsidies will also be available to people with incomes between 133 and 400 percent of FPL to limit out-of-pocket spending.

4. Insurance companies will be barred from denying coverage to anyone with pre-existing conditions. Insurance companies will be required to accept all individuals regardless of their medical history and health status.

5. Medicaid eligibility will be expanded to 133 percent of FPL. Health care reform will expand Medicaid to all individuals under age 65 with incomes up to 133 percent of the FPL. Under the current law, FPL limits for Medicaid eligibility vary by state and adults under age 65 without dependent children are not eligible for the program in all states.

6. Adjusted community rating takes effect, requiring insurers to end the practice of charging different premium rates for men and women.

7. Out-of-pocket limits will be capped for individuals with income up to 400 percent of FPL. This rule is designed to keep out-of-pocket limits within health savings account requirements, and ultimately, to prevent medical bankruptcy.

2018: The laws impose a 40 percent excise tax on high-end insurance policies (aka “Cadillac Plans”). This tax will be paid by the insurer providing the plan.

The Debate

There was much disagreement about health care reform, with arguments advanced for no changes to the system, to dismantling and replacing the existing system with a national health system (like Canada or Britain), and everything in between. In the end, the system is largely intact with much tinkering around the edges.

While Oley members are likely expert in the health care system with which we interact, we are just as vulnerable, if not more so, to the possibility of losing coverage. With the current system, we are all one job loss, one college graduation, one divorce away from losing our insurance. This is untenable for those of us who rely on expensive health care to keep us alive. Paying out of pocket for HPN on even a short-term basis is simply impossible.

The health reform changes, while imperfect from a number of
perspectives, at the very least represent an attempt to make the connections to health insurance stronger for all of us. This is not universal coverage, so there will still be individuals who for the short or long term have no access to health insurance. But many of the holes in the system will be plugged over the next few years.

Most notably for Oley Foundation members, who often have a lifetime of health problems and multiple diagnoses, health insurers no longer will be able to refuse or deny coverage when we most need it.

Frances Culp has been HPN dependent due to malabsorption since 2005 and deals with a number of chronic health problems due to cancer treatment as a young child. She has a master’s degree in Health Advocacy from Sarah Lawrence College and works as a Health Planner for the San Francisco Department of Public Health.

For more information, refer to the Kaiser Family Foundation’s Web site. The Kaiser Family Foundation is an excellent non-partisan source of health policy information (www.kff.org).

Notes

1. A pre-existing condition is a condition, disease, illness, or injury for which medical advice, diagnosis, care, or treatment was received or recommended within a specified time period prior to enrolling in a health plan, or for which a reasonably prudent person would have sought medical attention. Insurers are known for defining this term widely, denying applicants for something as serious as cancer or heart disease, or as relatively minor as asthma or hay fever. At this time, insurers may use pre-existing conditions(s) as grounds for denial for individual health plans only; health status is not considered for group insurance (typically through an employer).

2. A study by the Commonwealth Fund found that 45 percent of young adults 19–29 went without health insurance for some period of time in the last year.

3. The high-risk pools will be phased out at this time, since by this time insurers must accept children and adults regardless of their medical situation/history. These exchanges will offer a new route to coverage for many.

4. Premium tax credits will be available even if you have no tax liability (i.e., they are “refundable”) and will allow you to receive assistance when you purchase insurance (i.e., they are “advanceable”; you do not have to pay the premium out of pocket and wait until you file your income tax return to be reimbursed).

The FPL is an income amount set by the federal government each year that defines the poverty line for all Americans. It is used widely in all states to determine eligibility for various public programs. In 2010, the FPL for a family of one is $10,830/year (133 percent is $14,403.90 and 400 percent is $43,320).
Fortunately my journey has been long, despite fate seeming to sometimes wish otherwise. I have had many opportunities to learn and the will to do so. However, now that I have the knowledge I still have to constantly keep an eye on myself or my compliance with my health regiment slips. Yet at the same time, I have to remember that a little bit of noncompliance, when planned, can keep me sane and keep me going another day. Compliance, at least for me, is a fairly complicated issue, so allow me to begin at my beginning.

**Long, Bumpy Road**

By the time I was sixteen I had received two major emergency surgeries, had been placed on a combination of parenteral nutrition (PN) and tube feeds (EN), and finally had a full diagnosis — and all of this happened within a six-month period. It was a lot to take in.

When I was discharged from the hospital I was not about to complain openly about all of the things I was supposed to do. But over the next couple of months — though I had the help of my parents and some nurses — I began to rebel in small ways. Perhaps I would eat something off my diet, or change my line dressing a little late. Or I might tax my body beyond what it could handle. Sometimes I rebelled in bigger ways.

**Ignorance Is Not Bliss**

Besides rebelling against the prescribed health regiment, there were also things my parents and I were missing simply because we did not know about them. I was being “noncompliant,” but not by choice. Whether willful or not though, not following orders in the first few months with HPN led to a lot problems for me.

I had one episode where I went insane and had to be restrained for a week due to a combination of pain meds I had been put on during a hospital stay for a bowel slowdown. Once I had a major blood infection and had to take medicine so harsh my entire body shook while I took it. Last, but not least, I had to undergo another major emergency surgery.

In point, I was probably lucky to see the new year due to noncompliance in my first few months on HPEN. Afterwards, the severity of my situation began to sink in. I took over the role my parents had previously filled and began doing my own medical care, and I began to be a bit more serious about staying healthy.

**A Lot to Learn**

Over the next couple of years I transitioned to full tube feeds and then to full HPN. Along the way I slowly learned more and more, and with each year I have been better able to comply with my doctors’ orders. This is because not only have I been getting better, but things are getting more “normal.” I am getting used to living such a different lifestyle.

I’ve still suffered some serious complications, blood infections and surgery included, and though sometimes it has been due to noncompliance, I have learned each time. Even with all the knowledge I now have, compliance is still a constant annoyance and problem, but at least it’s not a life-threatening danger anymore.

**Atlas in Action**

Unfortunately, depending upon the condition that leads you to require HPEN, and its severity, you could need to have the knowledge of — at minimum — a trained nurse practitioner to take care of yourself. Being
a young man who is supposed to be coming into his prime, I try to do everything for myself. As you can imagine, this leads to problems.

Doing everything for myself includes being my own nurse, ordering supplies weekly, scheduling drop off of said supplies, organizing medical insurance coverage, calling doctors, and, of course, the process of hooking up to and unhooking from HPN, as well as accessing my port.

In addition to the seemingly endless inundation of boring work and at times stressful procedures that come with being my own nurse, I must constantly comply regarding a plethora of other issues. These include watching calorie loss and calorie gain carefully; doing a bit of exercise whether I feel bad or not; and holding back when I feel like a million bucks. I also, of course, have to strictly watch my diet. Usually this means not eating anything at all, while keeping in mind that not eating could lead to liver disease.

Constantly complying with the ins and outs of having my disease often leaves me breathless. When I already have exhaustion issues, having any sort of life outside of my disease can be near impossible. I can think of nothing more infuriating than finding even the simple things in life are too much to handle because I used what little energy and will I had had to deal with medical concerns.

For this reason I may never be rid of dealing with compliance. As long as I have to choose between enjoying life and complying with the routines made necessary by my many medical issues, I will always rebel a bit — for as long as I am sane and willing to keep fighting. I do not believe anybody can be asked to be that perfect, or, in my view, to become that boring.

Atlas Takes a Break

Having so much on my plate, there are times when I ask myself if I can do it all, and at times the simple truth is no. I hit this wall soon after my first surgeries, when my illness truly started to affect me physically. Instead of listening to my family, my doctors, my body, or just plain common sense, I rebelled against my constraints.

This was not a good idea. The indiscretions often landed me back in the hospital. But with some help and a bit of luck I made it through. And, despite the fact that I did rebel and it was dangerous, at times I felt there was nothing else I could have done.

Part of the reason I believe I am still hopeful and strong, and still willing to push on, is because of my insanely stubborn nature. So if you are a caretaker or family member with a rebellious consumer on your hands, be vigilant, but also be somewhat thankful — their stubborn nature may help them push on, too.

Dog Tired

On the other side of noncompliance because of rebellion and dissent is noncompliance due to a loss of hope and an absence of energy. Some days things seem to be too tough. All the physical issues, combined with everything else, can really feel like too much. It is hard to do anything at all.

At these times really can be incapable of taking care of myself. For that reason I think it is essential to always have friends, family, and caretakers on hand. They can help me, but more importantly they need to kick my butt every once in a while, and tell me how lazy I am being...even if they are being hypocritical, as most healthy people are.

Even if your situation truly is overwhelming and you truly feel like you can’t do anything, it can be useful to have people there to push you a little. Having an illness can be a rigorous balancing act. You cannot push yourself too hard, but to let yourself give up can be far more dangerous. So even if it makes you angry, even if you feel they do not have the right, be thankful if you have someone who wants more for you.

Don’t Give Up

So what can we do to keep up compliance? Try, try, and try again. The more you do it the easier it becomes, and with any luck you may get into a routine.

On days when the exhaustion, nausea, pain, or whatever is just overwhelming, focus only on finishing the essentials. Remember that not only will doing the basics with your health care help you feel better physically, but you will also have accomplished something.

It can truly be overwhelming to have to work so hard just to ensure you can see another day. I have had a lot of close calls in the past, and many times they have been because of, or related to, my choices. This can be hard to accept. But doing so gives me hope that with maturity I may find it easier to comply with the many things I know I should be doing. And with that will come much more for me to enjoy.

In fact, I am already seeing the benefits. I just can’t let myself stop trying.
**Spotlight on Our Corporate Partners**

Please join the Oley Foundation in thanking our most recent corporate contributors. Without their support Oley could not provide many of its many programs free of charge to home parenteral and enteral consumers. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

**Emmaus Medical, Inc.**

Emmaus Medical, Inc., is a Torrance, California, private pharmaceutical company dedicated to developing and bringing to market new treatments for rare diseases and conditions. Emmaus Medical launched its first product, NutreStore® (L-glutamine powder for oral solution), the first prescription L-glutamine available in the United States, in June 2008, and received exclusive rights to market Zorbative® (somatropin [rDNA origin] for injection) in December 2008.

Emmaus Medical is currently conducting clinical trials to investigate the safety and efficacy of oral L-glutamine for sickle cell disease. The company writes, “Emmaus is excited to partner with the Oley Foundation to help reach out and provide education to all patients, especially those with short bowel syndrome.” We are grateful for their continued support at the Bronze Star level.

**Applied Medical Technology**

Applied Medical Technology, Inc. (AMT) was present at the birth and development of the percutaneous endoscopic gastrostomy (PEG) movement. The company’s founder co-invented the first button low-profile feeding device. “Since then,” the company writes, “AMT has introduced innovative designs and materials to advance PEG tubes by increasing patient comfort while improving patient outcomes. AMT’s Mini ONE® Balloon and Non-Balloon Buttons have unique design features that provide increased patient comfort and long life.”

The company’s products are compatible with other manufacturer’s feed sets as well as its own feed sets and accessories. We thank AMT for its continued support at the Patron level.

**Critical Care Systems**

Critical Care Systems is a leading national specialty infusion company providing comprehensive clinical services to pediatric and adult populations through a national footprint of JCAHO-accredited community-based branches.

Their Specialty Nutrition Support Program is supported by a team of dietitians, nurses, pharmacists, and reimbursement specialists well versed in parenteral nutrition (PN), clinical support, and customer service. “Whether our customers require shorter or longer term therapy,” they write, “we provide flexible, individualized care adapted to the consumer’s lifestyle. It is our belief that customized nutrition support, ‘state of the art’ Standards of Practice, and a team of PN experts lead to optimal outcomes. Our 97% percent satisfaction rate demonstrates that ‘Patients are the center of all we do.’ We are proud to support the Oley Foundation.” The Oley Foundation is grateful for the support Critical Care Systems has provided over many years.

**Equipment-Supply Exchange**

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Check out the Oley Foundation’s Equipment-Supply Exchange!

A full listing of items available—from tubing and bags to formula to durable items—is posted on the Oley Web site. This list is updated every Monday, so check frequently. If you see something you need, or want to donate something you don’t need, contact Oley volunteers, Tammi and Rob Stillion at Oleyequipment@aol.com, or call toll-free, (866) 454-7351 between 9 a.m. and 4 p.m. EST. When e-mailing a request, be sure to let them know which item you are requesting and give a reference/reorder number if it’s available.

**Pump, from pg. 1**

on-screen instructions; and mechanical or electrical failures, including components that break under routine use, premature battery failures, and sparks or pump fires.

As part of its initiative, the FDA has published guidelines recommending that pump manufacturers begin to provide additional design and engineering information to the agency during premarket review of the devices. Consumers can comment on the draft guidance, which can be accessed from the FDA Web page noted below. Comments can be sent to Division of Dockets Management (HFA-305), FDA, 5630 Fishers Lane, Rm. 1061, Rockville, MD 20852 or www.regulations.gov. Refer to Docket No. FDA-2010-D-0194. The FDA has also offered manufacturers the option of having their software codes analyzed by experts at the FDA.

The FDA has developed a Web page featuring basic information about infusion pumps and listing steps consumers and clinicians can take to prevent and report safety problems. Consumers and clinicians are encouraged to report problems. Visit this new page at www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/GeneralHospitalDevicesandSupplies/InfusionPumps/default.htm

In May the FDA held a public workshop regarding infusion pumps. Participants discussed observed safety problems and ways to improve pump design. A summary of the meeting is available on the FDA Web page noted above. If the FDA announces additional public workshops, we encourage you to participate, and will post information on the Oley Web site (www.oley.org) as it becomes available. Watch the FDA Web page for announcements also.

You may also be interested in the FDA’s Home Use Devices Initiative. More on this at www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/HomeHealthandConsumer/HomeUseDevices/ucm208268.htm.

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Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share the list of honorees in each issue of the newsletter. A complete list of contributions will be published annually in the Jan/Feb issue of the LifelineLetter and in the Oley Annual Report.

Between March 17, 2010, and June 1, 2010, gifts were received:

Acknowledging
Mary Kunz’s birthday
Michael Medwar’s 40th birthday

In Memory of
Catherine Carroll
Robin K. Lang
Colyn Woods

In Honor of
Bradford Murray

Toward
Robin Lang Travel Scholarship

We appreciate all gifts, and the kind comments that we receive throughout the year. Your support overwheels us and continues to be a source of inspiration. Thank you!

Oley Horizon Society Blossoms!

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at (800) 776-OLEY.

Felice Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Katherine Cotter
Jim Cowan
Rick Davis
Ann & Paul DeBarbieri
David & Sheila DeKold
Tom Diamantidis, PharmD
Selma Ehrenpreis
Herb & Jay Emich
Jerry Fickle
Don Freeman
Linda Gold
Linda Gravenstein
The Groebner Family
Valerie Gyurko, RN

Alfred Haas
Shirley Heller
Alicia Hoelle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kathore Iyer, MD
Darlene Kelly, MD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Laura Matarese, PhD, RD, CNSD
Kathleen McNees
Michael Medwar
Meredith Nelson
Nancy Nicholson
Rudolph & Paula Okamoto, RPh

Kay Oldenburg
Judy Peterson, MS, RN
Clemens Pfeitzner
Beverly Promisel
Abraham Rich
Gail Egan Sanniverso, MS, ANP
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schemol
Doug Seidner, MD, FACC, CNSP
Judi Smith
Steve Swensen
Cheryl Thompson, PhD, RD, CNSD, & Gregory A. Thompson MD, MS:
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Roseline Ann & William Wu

Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their continued interest and strong commitment.

PLATINUM LEVEL PARTNERS
($70,000+)
Nutrishare, Inc.

GOLDEN MEDALLION PARTNERS ($50,000–$69,999)
Coram Specialty Infusion Services
ThriveRx (formerly NutriThrive)

SILVER CIRCLE PARTNERS
($30,000–$49,999)

BRONZE STAR PARTNERS
($20,000–$29,999)
Emmaus Medical, Inc.

BENEFACTOR LEVEL PARTNERS
($10,000–$19,999)
Abbott Nutrition
InfuScience, Inc.
Nestlé HealthCare Nutrition

PATRON LEVEL PARTNERS
($5,000–$9,999)
Applied Medical Technology, Inc.
Baxter Healthcare
Critical Care Systems, Inc.
NPS Pharmaceuticals
Walgrens-OptionCare

BLUE RIBBON PARTNERS
($2,500–$4,999)
Kimberly-Clark
Sherwood Clinical

CONTRIBUTORS
($1,000–$2,499)
B. Braun Medical
Moog Medical Devices Group/Zevex
FDA Resource on Investigational Drugs

In late 2009, the U.S. Food and Drug Administration (FDA) approved new rules designed to allow seriously ill patients greater access to investigational, or trial, drugs. Investigational drugs may be made available to a participant in a clinical trial, or to others under an expanded access (or “compassionate use”) program.

Want to learn more? Visit the FDA Web site at http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/AccessToInvestigationalDrugs/default.htm.

A.S.P.E.N. Releases EN Book

Though it is written for clinicians, home enteral (HEN) consumers and/or their caregivers may find the new Enteral Nutrition Handbook, published by the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and edited by Joseph Boullata, PharmD, RPh, BCNSP, Liesje Nieman Carney, RD, CNSD, LDN, and Peggi Guenter, PhD, RN, CNSN, very useful.

The chapters most likely to interest HEN consumers/caregivers include those focused on EN formulas, complications of EN, medication administration with EN, and HEN issues, such as home care providers and nutrition support teams.

The handbook is available for $39.95 (plus shipping) through A.S.P.E.N., www.nutritioncare.org or (301) 587-6315.