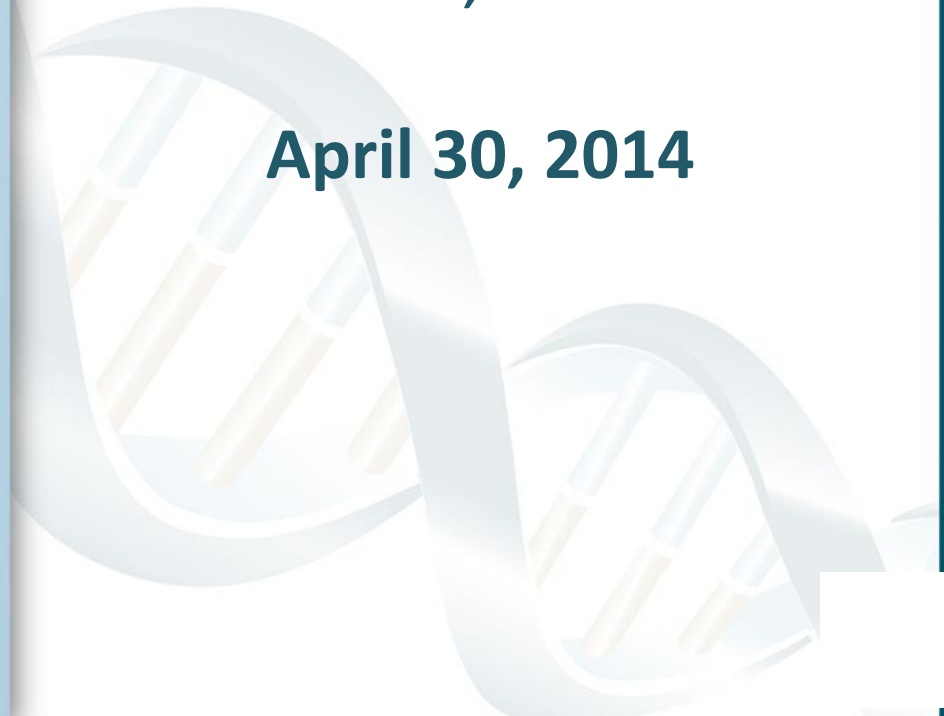


**Global Genes™**  
Allies in Rare Disease

## Navigating Insurance Issues, Part 1

**April 30, 2014**



# Submit Your Questions

There will be a Q&A Session  
at the end of the webinar  
presentation.

To ensure your questions get  
answered, please use  
WebEx's Q&A feature  
and direct your questions to  
the Global Genes  
representative (or Host),  
Katie Mastro

Feel free to submit questions  
throughout the presentation





# Health Insurance 101

James Romano,  
Director of Government Relations

# What is Insurance?

- Insurance is the transfer of risk from one entity to another in exchange for payment
- Risk Management, again unexpected loss
- Types of Insurance
  - Car Insurance
  - Liability
  - Accident
  - Life
  - Long Term Care



# What is Health Insurance?

- Health Insurance is a way to pay for healthcare
- Protects individuals from paying the full costs of medical services
- Individuals chooses a plan with defined benefits
- Individual pays a premium on a defined basis (monthly, quarterly, or annually)
- Insurer agrees to pay a portion of your covered medical costs



# Competing Interests = Complications

- **Individual:** wants to access affordable, quality care
- **Payer:** for-profit enterprise that controls costs
- **Employer:** offers competitive benefits, including comprehensive health insurance at low premiums

# Types of Insurance Coverage

## Two Types of Insurance Policies:

- Private Insurance - Employer sponsored or individual plans
- Public Insurance - Government

# How is America Covered?

## Kaiser 2012-2013 Survey on Insurance Coverage

- 48% of Americans are offered insurance through employer
- 5% of Americans obtain insurance from other markets
- 16% of Americans obtain coverage through Medicaid
- 14% of Americans obtain coverage through Medicare
- 1% obtain coverage through other public programs
- 15% of Americans are Uninsured



# Glossary of Key Terms

**Medical Benefit (Major Medical):** Part of insurance coverage associated with serious illness or hospitalization. Plans have a set amount or deductible

**Pharmacy Benefit:** Either stand alone or integrated coverage for treatments and therapies

**Premiums:** The amount the policy holder pays to the health plan to purchase health coverage

**Deductible:** The amount the insured must pay out of pocket before the health insurer pays its share

**Co-payment:** The amount the insured person must pay out of pocket before the health insurer pays for a particular visit or service



# Glossary of Key Terms (cont.)

**Co-Insurance:** A percentage of the total cost of treatments that the insured may also pay. An example 20% of the cost while the Insurance Provider pay 80%

**Pre-Existing Condition:** A medical condition, that in the past could have prevented from obtaining coverage

**Catastrophic Coverage:** A health plan that covers essential health benefits but has a very high deductible. This provides a safety net in case of accident or serious illness

**Utilization Management:** the evaluation of the appropriateness, medical need and efficiency of healthcare services, procedures, and facilities according to established guidelines and under the provision of the plan.



# Glossary of Key Terms (cont.)

**Prescription Drug Formulary:** Specify particular medications that are approved to be prescribed under a particular insurance policy

**Formulary Specialty Tier:** A plan may cover prescription medications in four levels based on cost, with the individual's costs increasing as the level increases

**Prior Authorization:** Individual or doctor needs' permission from the insurance company before a pharmacy will fill a prescription

**Step Therapy:** The practice of using the most cost effective therapy first then moving toward more costly therapies if necessary. Also known as Fail First.



# Public Health Insurance

**Medicare:** Medicare Insurance Program for people age 65 years or older, certain younger people with disabilities and people with ESRD.

**Medicaid:** Social insurance program for families and individuals with low income. Federal and State partnership.

**SCHIP:** State and federal insurance partnership aimed at covering uninsured children in states.

**Tricare:** Health insurance coverage through the United States Military, retirees and dependents

**VA Benefits:** Health benefits for military veterans



# PRE-ACA Health Protections (COBRA)

**COBRA:** Government legislation that allows an employed person to take his/her group health insurance policy when leaving employment.

- The patient can keep insurance up to 18 months with conditions up to 36 months
- Individuals are responsible for the premium and admin costs
- Individuals have 60 days to elect COBRA and 45 days to pay the first premium



# PRE-ACA Health Protections (HIPAA)

- Credible coverage applied towards new policy
- Exhausting COBRA
- Must be covered 18 months or longer w/previous insurance company, preventing pre-existing waiting period
- Under Group Health Insurance
  - There is usually no pre-existing waiting period
  - If you have exhausted COBRA, you cannot be denied coverage based on health status
- Under Individual Health Insurance
  - A policy may or may not be offered from a group policy to an individual policy
- Instituted Privacy Protections





# How Has Health Insurance Evolved?

Joel White, Founder & President



# What is the ACA – Affordable Care Act?

- Most sweeping reform of health insurance and health care since Medicare (1965)
- Impacts every American in some way
- Expands private and public coverage and subsidizes its purchase.
- Financed by tax increases and entitlement cuts (Medicare)
- Redistributes incomes and creates winners and losers
- Highly contentious and political– we are still fighting





# What is the ACA?

## Mandate

### What is Required of Me?

- Individual Mandate
- Employer Mandate

## Products

### What Do I Buy and When?

- 2014 – Qualifying events
- 2015 – Open enrollment
- Market Reforms

## Marketplace

### Where Do I Get Coverage?

- Exchanges – State, Partnership, Federal (healthcare.gov)
- Medicaid expansion

## Affordability

### How Will Costs Impact Me?

- Premium and Cost Sharing Subsidies
- Plan Attributes
- How will employers respond?

# What is Required of Me?



## Individual

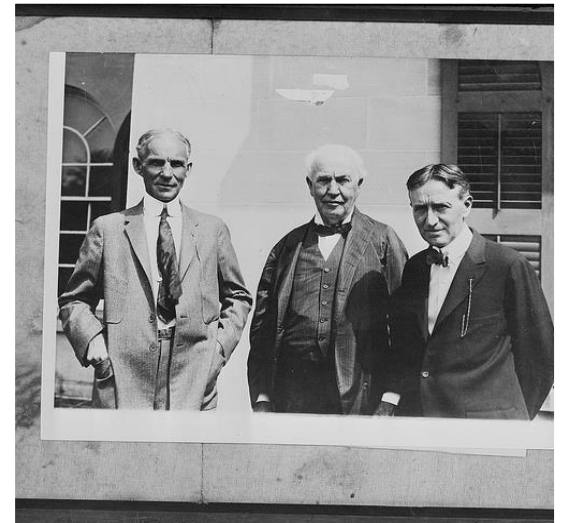
Buy coverage or pay a tax. The greater of:

2014: \$95;	OR	1%
2015: \$325;		2%
2016: \$695, indexed thereafter 2.5%		

## Employer

Provide affordable coverage or pay a tax.  
Sets penalties for employers with at least 50 FTEs that have at least one employee who receives a tax credit:

- Employers that offer coverage: fee is \$3,000/employee receiving credit or \$2,000/full time worker
- Employers who do not offer coverage: tax is \$2,000/FTE
- Penalty is reduced by 30 full time employees
- FTEs counted as 30 hours or more per week



# What is Required of Me?

1. Buy new coverage or
2. Continue acceptable existing coverage or
3. Get an exemption or
4. Pay a tax

Must have minimum essential coverage, defined by the source of coverage, which includes:

- an employer-sponsored plan,
- a government-sponsored program, such as Medicare or Medicaid,
- a grandfathered health plan,
- a plan in the individual market purchased on or off the public Marketplace, or
- other coverage – such as that offered through state health benefit risk pools – approved by the Department of Health and Human Services (HHS).

Does not include excepted benefits, such as short-term, mini-med or dental-only coverage.

## Exemptions:

- Coverage is unaffordable
- Don't file taxes
- Indian tribe member
- Coverage gap < 3 months
- Religious objections
- Unlawful entrants
- Prisoners
- Hardship

# Qualifying Events, Open Enrollment

**Open Enrollment:** Ended March 31, 2014. The Open Enrollment Period for 2015 coverage is November 15, 2014 – February 15, 2015.

**Special Enrollment Period:** Is a time outside of the Open Enrollment period during which you have a right to sign up for coverage.

- Generally 60 days following certain life events.
- If you don't have a special enrollment period, you can't buy insurance through the Marketplace until the next Open Enrollment period.

## **Qualifying Events:**

- Marriage, having a baby, adopting a child or placing a child for adoption or foster care, moving your residence, gaining citizenship, leaving incarceration
- Losing other health coverage. Voluntarily ending coverage doesn't qualify you for a special enrollment period.
- Having a change in income or household status that affects eligibility for subsidies
- Gaining status as member of an Indian tribe.

**Appeals:** You can appeal a decision to deny you a special enrollment period.

**Medicaid and CHIP:** You can apply for Medicaid and CHIP coverage any time.

# What Do I Buy?

<b>Essential Health Benefits</b>	Must cover 10 categories of essential health benefits, including prescription drugs
<b>Actuarial Value</b>	Cost sharing (% covered by plan) is determined by metal levels – Bronze (60%), Silver (70%), Gold (80%), Platinum (90%)
<b>Out of Pocket Limits</b>	Annual max cap of \$6,350 for individuals & \$12,700 for families in 2014. Out of network doesn't count.
<b>Annual and Lifetime Limits</b>	No lifetime limit or yearly limit on essential health benefits. Yearly effective in 2014.
<b>Pre-Ex Conditions</b>	Prohibits exclusions for pre-existing conditions (effective since 2010 for children under 19; effective in 2014 for adults)

# What Will Plans Provide?

## Coverage

- Guaranteed issue and renewal of coverage regardless of health status
- Young adults may remain on their parents' plan until age 26

## Essential Health Benefits

- Ambulatory patient services;
- Emergency services;
- Hospitalization;
- Laboratory services;
- Maternity and newborn care;
- Mental health and substance use disorder services, including behavioral health;
- Prescription drugs;
- Preventive and wellness services and chronic disease management;
- Rehabilitative and habilitative services and devices; and
- Pediatric services, including oral and vision care.

## Premiums

- Premium rating based on health status is prohibited
- Premiums allowed to vary by age (3:1), tobacco use (1:1.5), policy type (individual or family), and geographic location.
- May provide 30% discount if enrolled in a qualified wellness program





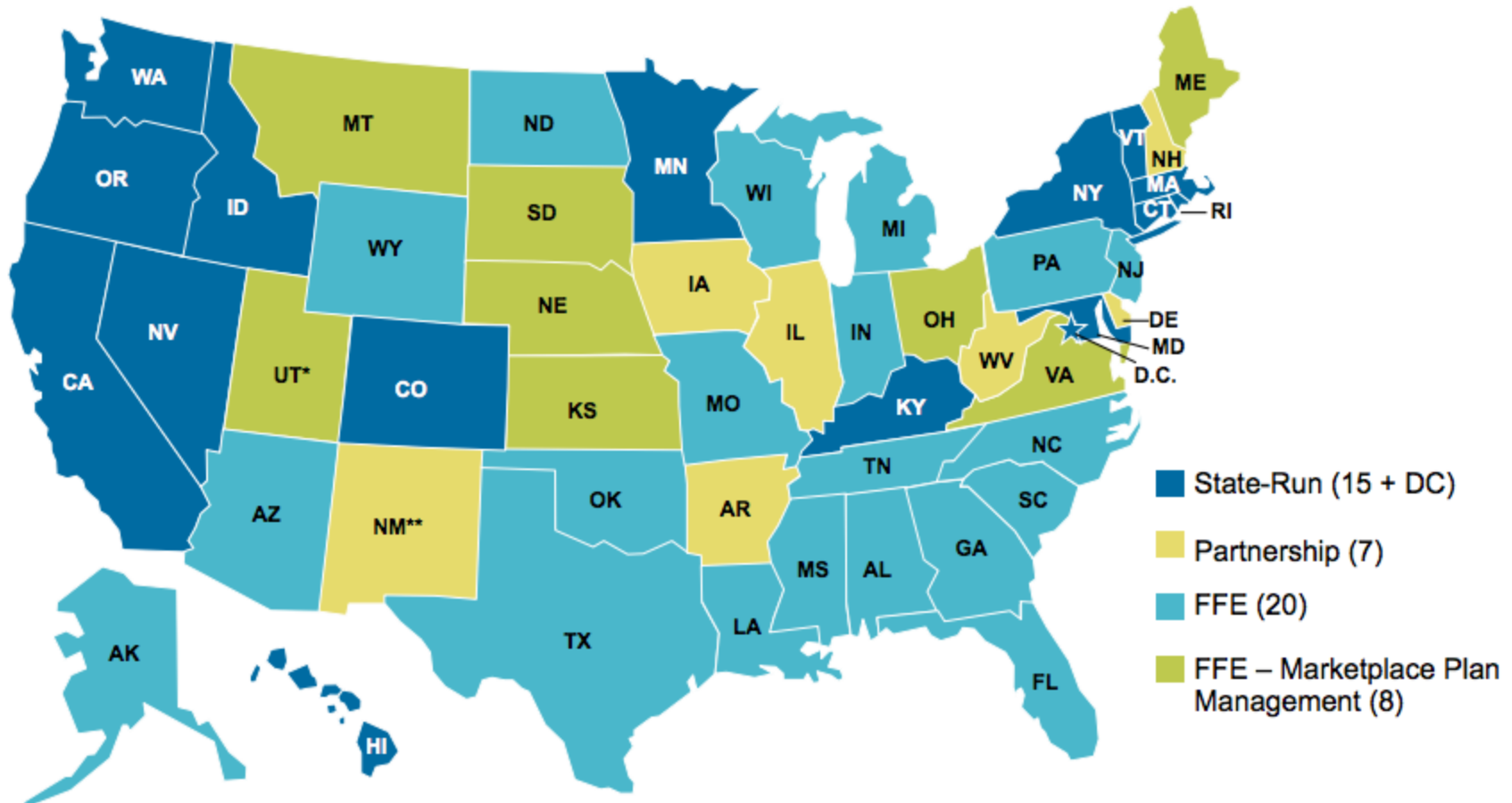
# Where Do I Get My Coverage?



- Individual Exchanges:
  - State-run
  - Partnership
  - Federal (healthcare.gov)
    - 8 million in 2014
    - 26 million by 2023
    - 21 million subsidized
- SHOP Exchange for Businesses delayed in 2014
  - 2015: Employers with 1 to 50 employees
  - 2016: 1 to 100, states may limit to 50
  - 2017: states may expand to groups with 101 employees or more

# Majority of States Will Rely on Federal Government to Operate or Assist with New Marketplaces in 2014

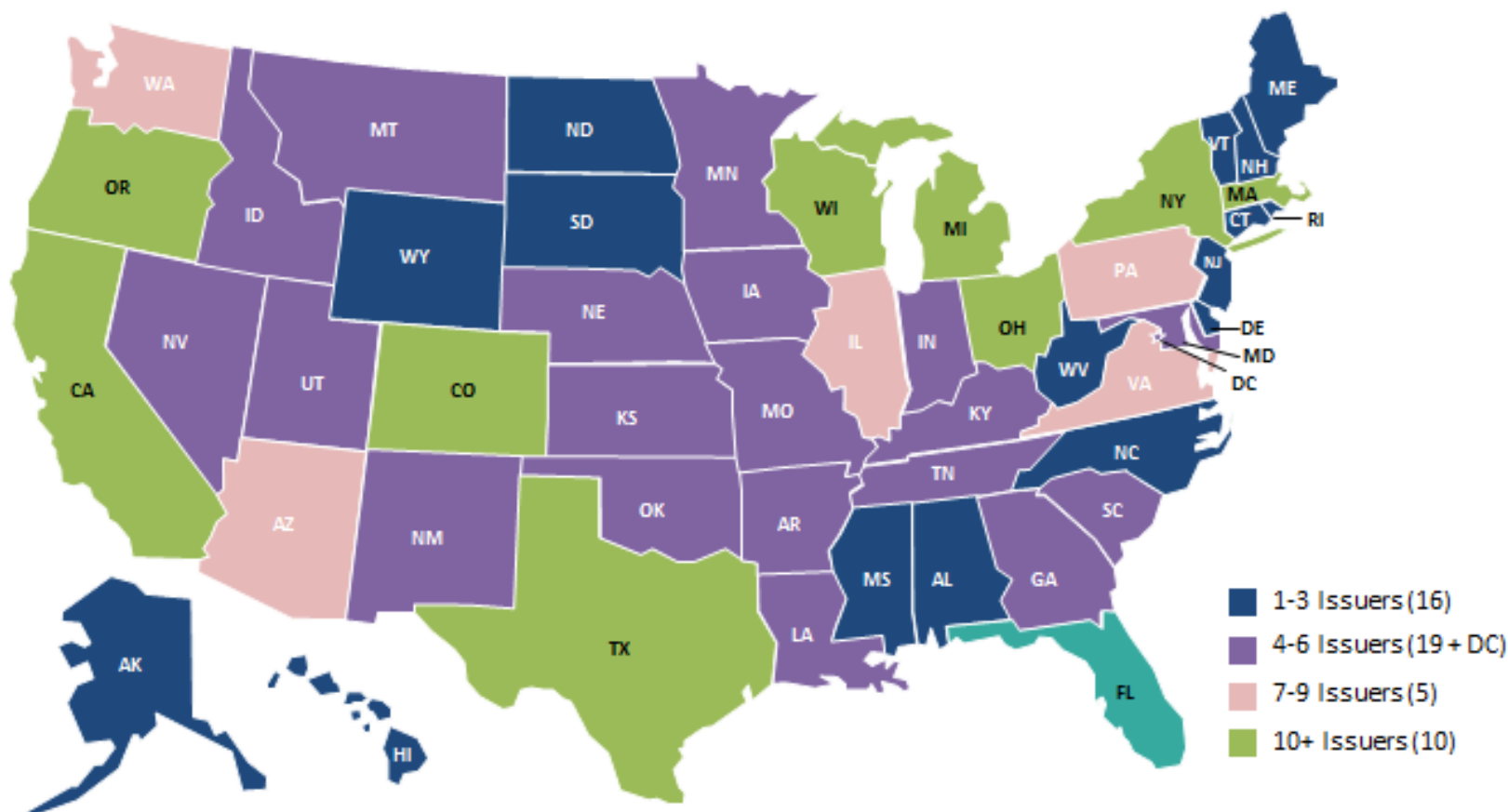
## Insurance Exchange Operational Model



Source: Washington Post, Avalere, Kaiser Family Foundation



# Issuer Competition By State, Individual Market



Source: Avalere Analysis of information available on healthcare.gov at: <https://data.healthcare.gov/dataset/QHP-Individual-Medical-Landscape/ba45-xusy>, accessed October 3, 2013, and *Avalere State Reform Insights*, February 18, 2014.

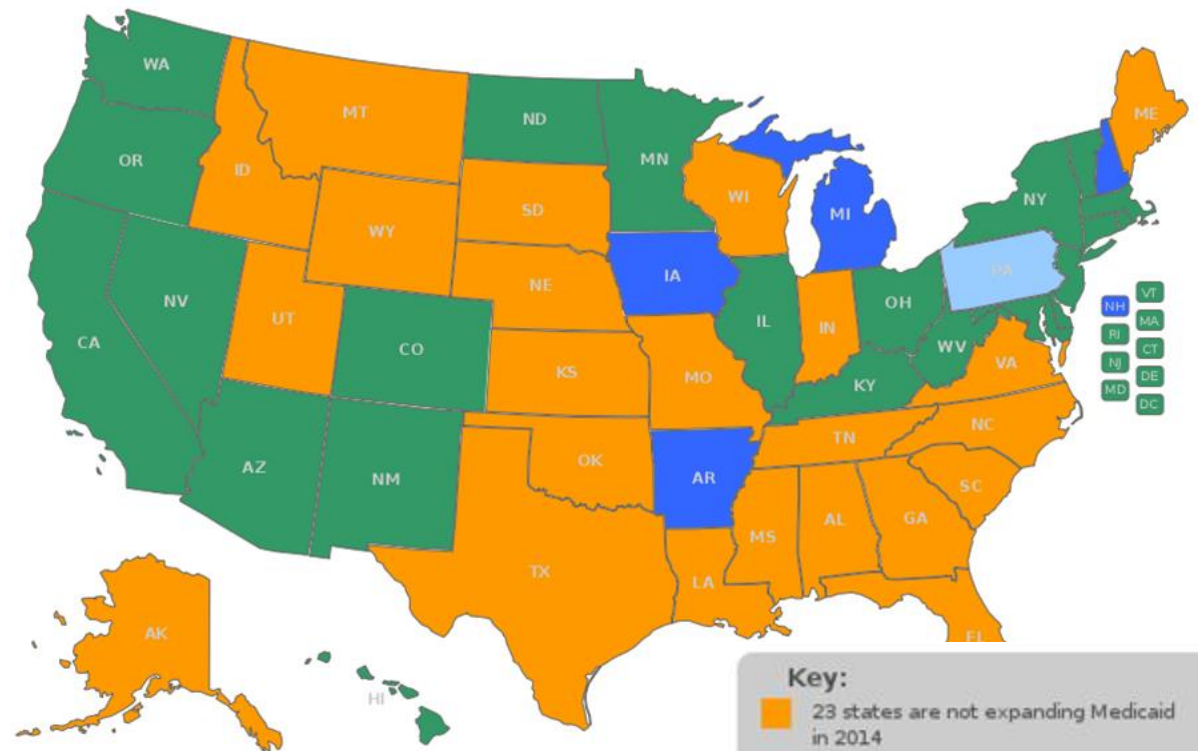
\*Issuer competition includes the OPM multi-state plan.

# Medicaid Expansion

\*Map updated April 25, 2014

The health reform law, for the first time, allows an individual to qualify for Medicaid based on income alone, but only in states that have agreed to expand their program.

Nearly all U.S. citizens under 65 with family incomes up to 138 percent of poverty (\$32,913 for a family of four in 2014) will qualify for Medicaid in states that have expanded the program.



## Key:

- 23 states are not expanding Medicaid in 2014
- 23 states (count includes the District of Columbia) are expanding Medicaid in 2014
- 4 states are expanding Medicaid in 2014, but using an alternative to traditional expansion
- 1 state with Medicaid expansion waivers pending approval from CMS

# How Will ACA Impact What I Pay?

- Premium Subsidies
- Cost-sharing Subsidies
- Reinsurance
- Pooling

**Lowers  
Costs**

- Rating Rules
- Actuarial Value
- Essential Health Benefits
- Pre-ex, GI, Individual mandate
- Medical cost trend
- New taxes (insurance, reinsurance, etc.)

**Increases  
Costs**

# How will Costs Impact Me?

**Premium Subsidies:** Tax credits that reduce premium as a percent of income. Applies to the second lowest cost Silver plan available in the exchange

Income	Premiums Limited to % of Income
<133% FPL	2.0%
133 – 150% FPL	3.0 – 4.0%
150 – 200% FPL	4.0 – 6.3%
200 – 250% FPL	6.3 – 8.05%
250 – 300% FPL	8.05 – 9.5%
300 – 400% FPL	9.5 %

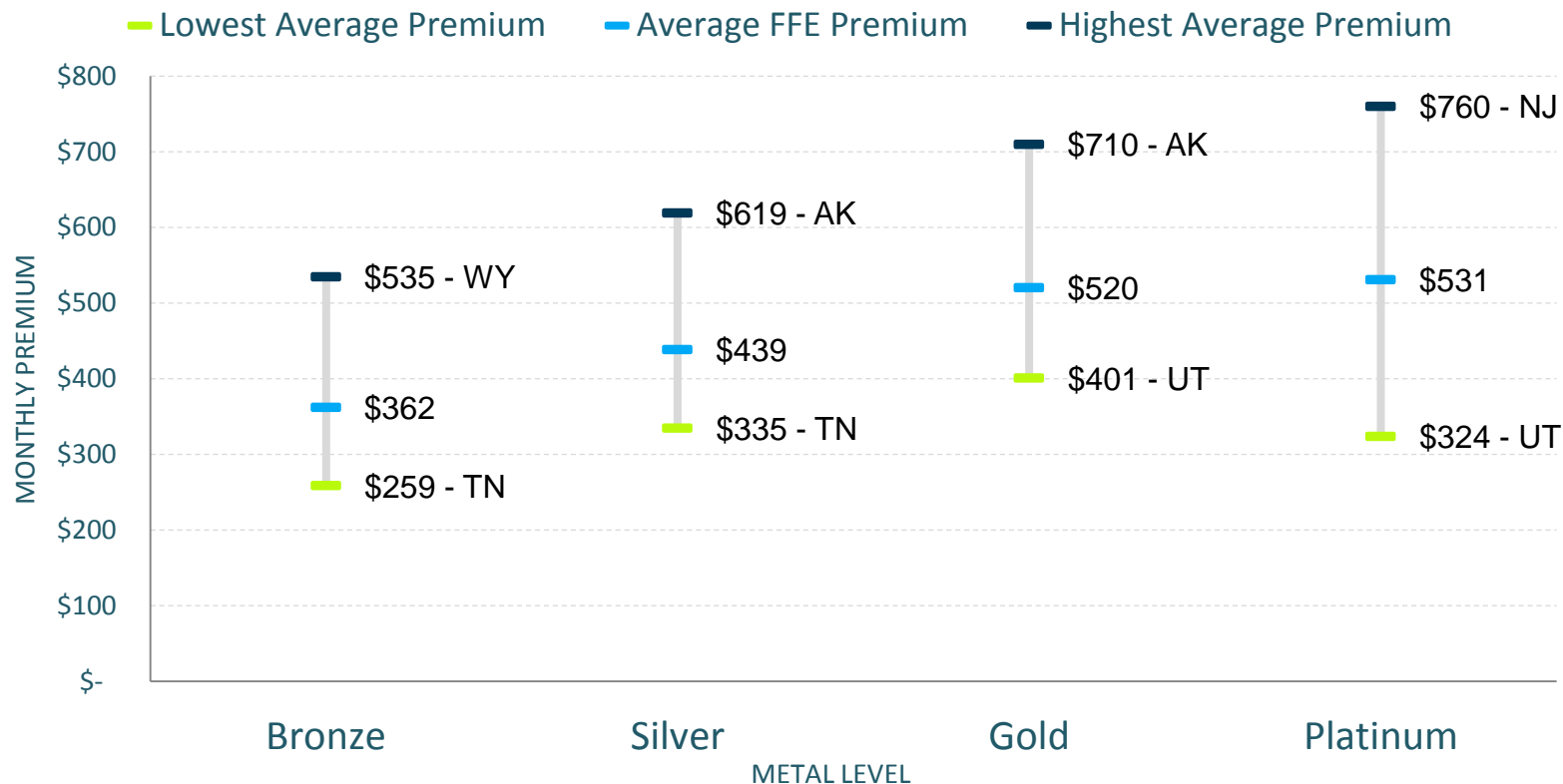
Household Size	Exchange Subsidy Income Limits	400% FPL	Medicaid Income Limit
1	100% FPL	\$46,680	138% FPL
2	\$11,670	\$62,920	\$16,105
3	\$15,730	\$79,160	\$21,707
4	\$19,790	\$95,400	\$27,310
	\$23,850		\$32,913

**Cost Sharing Subsidies:** Provides cost-sharing subsidies for individuals with incomes below 250% FPL. Cost sharing subsidies subject to sequester.

Household Income	Reduction in OOP Limit	Actuarial Value
100 - 150% FPL	2/3	94%
150 – 200% FPL	2/3	87%
200 – 250% FPL	1/5	73%
250 – 400% FPL	None	70%

# Premium and Cost-Sharing Subsidies

## AVERAGE PLAN PREMIUMS FOR 50 YEAR OLDS IN FEDERAL EXCHANGE STATES BY METAL LEVEL



Source: Avalere Analysis of information available on healthcare.gov at: <https://data.healthcare.gov/dataset/QHP-Individual-Medical-Landscape/ba45-xusy>, and Avalere State Reform Insights, October 15, 2013.

# How Have Plans Responded?

## Plans Came Into Marketplace With Competitive Premiums

- The law restricts plan flexibility:
  - Rating Rules
  - Actuarial Value
  - EHB
  - Taxes
- Costs must be made up to make business viable:
  - Higher premiums
  - Higher cost sharing
  - More restrictive coverage
  - Better risk pools

## With Pressure to Keep Premiums Low, Plans Must Find Ways to Lower Costs

- **Network Design:** Narrow networks of providers of high quality, lower costs or both
- **Cost-Sharing Requirements:** Deductibles and other cost-sharing requirements are more expensive than typically seen in employer markets
- **Formulary Design:** Tier placement and utilization management help plans manage drug use while still meeting EHB drug coverage requirements

# What Are Employers Doing?



Invest in wellness/prevention



- Reduce hours, hires
- Discontinue coverage

## All Employers

- 90% have moved beyond wait-and-see mode. Compliance is top focus.
- 64% have analyzed ACA's cost impact. Most estimate a 3-4% cost increase in 2014.
- Employers are or will implement cost-management initiatives due to the ACA: increase premium costs, deductibles, out-of-pocket limits.
- 17% working to avoid 2018 Cadillac tax
- 16% have adjusted or plan to adjust hours so fewer employees qualify as full-time.

# HORIZON

GOVERNMENT AFFAIRS

## *Questions*

Jwhite@horizondc.com

202-559-0192

Horizondc.com



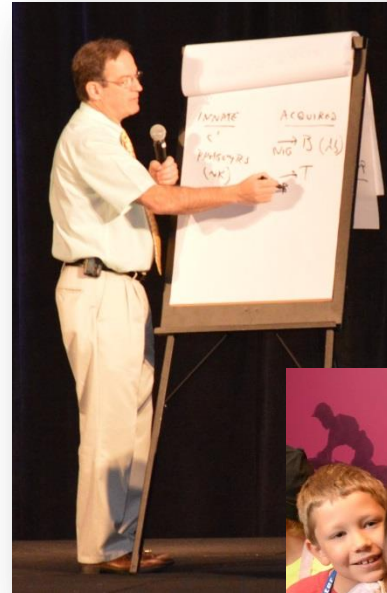


# What You Need To Know When Picking a Health Plan

Lawrence A. La Motte  
Vice President, Public Policy

# Mission Statement

Founded in 1980, the Immune Deficiency Foundation is a national patient organization in the United States dedicated to improving the diagnosis, treatment and quality of life of people with primary immunodeficiency diseases through advocacy, education and research.



# Picking A Plan Is Hard Work

There are 2 prime things to consider when picking a plan:

- **Benefit design**
  - General Health care needs
  - Rare disease specific care needs
- **Cost**
  - Premiums
  - Deductibles
  - Co-payments
  - Co-insurance



# Benefit Design – General

- What services does the plan cover?
- Are my physicians in the network?
- Are there annual limits to the number of visits for any particular service (for example, physical therapy)?
- Are out-of-network benefits available?  
What percentage of the cost am I responsible for if I receive out-of-network care?
- Am I covered if I get sick or need treatment out of state?



# Benefit Design – Rare Disease Specific

- Is your specific rare disease treatment covered? If yes, is it:
  - Part of the Major Medical part?
  - Part of the Pharmacy benefit part?
- Do I need a referral to see a specialist?
- Is a pre-authorization necessary to get before treatment?
- If your treatment involves drugs, will you be required to do “step therapy” before you get the treatment of choice?



# Getting Answers Is **Not** Easy

## Relatively Easy Part

- Summary of benefits
- Drug/Pharmacy Formulary List
- Provider network directory

## Hard Part

- Medical Benefit formulary – Is the drug treatment you need on the medical benefit formulary list?
- Out of Network coverage information
- How to access your provider if she/he is not in-network and at what cost

**Most likely you will need to contact the insurer directly – which is a pain**



# Finding Answers

## Contacting the insurer directly

- Go to the insurer's website
  - Look for coverage options or a listing of plans
  - Look for case managers who may be able to help answer questions
- Most plans have a Customer Assistance telephone line
  - Ask for whoever can provide assistance in choosing



*If one is part of an employer plan,  
ask for help from the agent/agency who works with your employer.*



# Finding Answers

- Contact your Human Resources Department to help you get to the right person at the insurance company
- You need to be persistent. If a person can't help you, insist on speaking to their superior – **be polite but FIRM!!**
- Write your questions down and ASK your questions – there is no such thing as a “stupid” question



Remember there is **no one** better than you to advocate for yourself or your family!



# Out of Pocket Costs (OOP)

There are four components to OOP costs:

- **Premium** – the cost of having the plan
  - NOTE: for plans purchased in the ACA marketplaces, tax subsidies may be available to offset premium costs
- **Deductible** – Amount one pays before the insurer pays for benefits.
- **Co-payment** – Flat dollar amount for services and some drugs
- **Co-insurance** – One pays a percentage of the treatment or drug (this can get expensive)



# Access to Specialists

## In-Network Physicians and Hospitals

- Make sure all of your physicians are in-network
  - Making sure that your specialist is in-network is critical
  - If not, you will pay extra and usually a great deal extra for Out of Network coverage
- Make sure that your physicians have privileges at the hospitals of your choice too



# Obstacles to Care: Utilization Management

## Techniques to control “overuse” of expensive treatments

- Prior Authorization – Permission to have treatment **before** treatment
  - Very common for rare disease treatments
  - Very common for expensive drug treatments
- Restrictive Formularies
  - Reimbursement only for a limited number of drug treatments types
    - Limitations on certain drugs are allowed
    - Some rare diseases have multiple drugs to choose from – however, many are not interchangeable
    - Many rare diseases do not have a drug treatment or may have only one drug treatment



# Obstacles to Care: Utilization Management

## Techniques to control “overuse” of expensive treatments (con’t)

- Step therapy:
  - Patient must “fail” a treatment before being allowed to have an alternative treatment regardless of the opinion of a physician, OR
  - Patient must have an adverse reaction to a treatment before being allowed to have an alternative treatment

# Cost-Sharing

- Most people are familiar with premiums, deductibles and flat dollar amount co-payments
- Many people do not understand specialty tier co-insurance
  - A plan may require the patient must pay a percentage of the cost of treatment , if a specialty drug is used for treatment
  - By definition, a specialty drug is an expensive drug and is usually a biologic
  - Specialty tier patient co-insurance percentages can be anywhere between 20% and 50%
  - Many people think that this form of cost sharing is economic discrimination because most people can not afford the costs and thus forego care

# Co-insurance Example

Many patients with a primary immunodeficiency disease need lifelong monthly infusions of immunoglobulin (Ig), a blood plasma product. The antibodies in the Ig blood plasma product act as a temporary immune system for patients.

If the cost of a monthly infusion is \$7,500 per month and the health plan demands that patients pay 25% of the cost, the patient is on the hook for \$1,875 per treatment per month until they have reached the Affordable Care Act's out-of-pocket costs cap of \$6,350 for an individual and \$12,700 for a family in any given year.

*It will take nearly 7 months for the family to reach the cap (a little over 3 months for an individual plan), assuming no other health expenses during that time.*

# Homework

Review and write down all of the health services you and your family used in the preceding year:

- Include doctor visits, ER visits, hospitalizations, lab tests, and prescriptions
- Tally all of the out of pocket costs you incurred during the year.
  - Include premiums, deductibles, co-payments and co-insurance costs
- Estimate all of your anticipated and foreseeable costs for the coming year.
- If you are in the ACA marketplace, estimate what possible tax subsidy you may qualify for to offset premium costs





# Homework

For each plan to be evaluated, obtain from your HR department, agent, navigator or Insurance Marketplace:

- Summary plan description
- Drug formulary
- Provider Network Booklet
- Any information about Health Savings or Flexible Spending Accounts your employer might offer
- Glossary of insurance and medical terminology



# Homework

If you have a rare disease, the information you have collected will probably not be enough to make a decision

You may contact the insurance companies who sponsor the plan(s) you are evaluating to obtain the medical policies for your specific condition and ask specific questions about a company's medical policies, including any procedure codes for the treatments for your rare and/or chronic disease



# Summary

- Picking a Plan is now more complicated than it used to be— especially if you or a family member has a rare and/or chronic disease
- Keep records of everything related to healthcare costs.
- Seek out resources on the internet
- IDF's Health Insurance Toolkit may be helpful even though it is customized for patients with PI  
<http://primaryimmune.org/services/patient-insurance-center/idf-health-insurance-toolkit/>



# Closing Remarks



Time for Your Questions!

# Part 2 Registration is Open

## Navigating Insurance Issues, Part 2

May 28, 2014

10:00 am PST / 1:00 pm EST

Register today at

[https://globalgenes.org/navigating\\_insurance\\_issues\\_webinar\\_2/](https://globalgenes.org/navigating_insurance_issues_webinar_2/)

# THANK YOU!



*hope. it's in our genes.™*

[www.globalgenes.org](http://www.globalgenes.org)

hope.