# Managing Health Insurance in Thalassemia

Marla Feinstein
Senior Policy and Healthcare Analyst
National Hemophilia Foundation

NATIONAL HEMOPHILIA FOUNDATION

*for all bleeding disorders*

# Evaluating Access to Care

1. What is the type of coverage?
2. Who is the payer?*
3. Who regulates/oversees the payer?

*“Payer” is someone *other than the patient* that finance or reimburse the cost of health care services. In most cases, this term refers to insurance carriers, other third-party payers, or health plan sponsors (employers or unions).

# Why Reform?

## Challenges to Access to Care

**Challenges:**

- Access & Demand
  - 50-55 million uninsured
- Physician Shortage
- Rising Drug Costs
- Narrow networks
- Higher OOP costs

**Needs:**

- Improved patient coverage
- Improved patient access
- Improved outcomes of care
- Reduced costs for care

**Response:**

- Legislative
- Regulatory

# Affordable Care Act (ACA):

# What it Means for Rare Diseases

Increased access:

- Elimination of annual and lifetime caps on essential health benefits
- Elimination of Pre-existing conditions exclusions
- Expanded eligibility for those under age 26
- In some states, expansion of Medicaid eligibility
- Additional Coverage Options - Marketplace

# New Options = Increased Responsibility

## Choosing a Health Plan

Be prepared


Do your research


Choose wisely

# Insurance Coverage Options

- **Private Plans:**
  - Group/employer-sponsored plan
    - **Fully insured:** Premium costs shared by employer & employee; claims paid by insurer
    - **Self insured:** Premium costs shared by employer & employee; employer contracts with insurer to administer claims. Employer pays claims
  - Individual plan
  - Marketplace plan

- **Public Plans:**
  - Medicaid/CHIP
  - Medicare
  - TRICARE/VA

# Why Does the Type of Plan Matter?

Governing Authority

- Fully insured group plans & Individual plans: federal and state law
- Self insured group plans: ERISA (federal government)
- Medicaid: federal and state law
- Medicare, TRICARE & Veterans benefits: federal law

TIP: Knowing which type of plan you have and who has oversight of the plan dictates who you turn to for help

# Getting Started: Open Enrollment

When is open enrollment?

- Typically once a year
- Allows you to choose from one or more available plans
- Once chosen, no change in coverage until the next ***open enrollment*** **d**ate
- Exception: a **qualifying life event -** Death, termination of employment, divorce, terminal illness

# The Perfect Policy Does Not Exist!

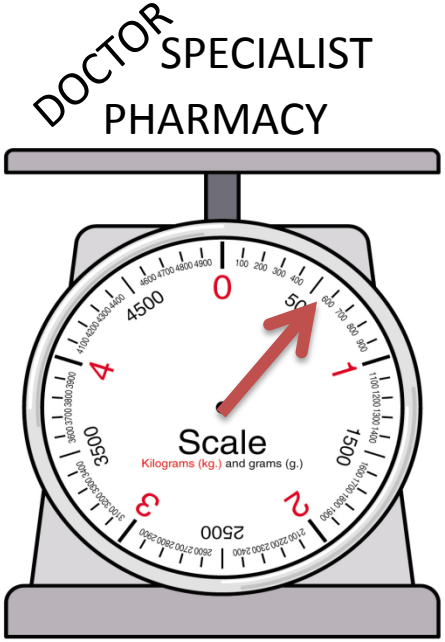
- Choices will have to be made:
  - What benefit options do you NEED?
    - Which are most important to insure optimal outcomes in you or your loved one's health?
    - Prepare a list of the services/providers you need – be SPECIFIC and inclusive!
  - What benefit options do you WANT
    - Which benefits/services add convenience to you or your loved one's care
- What are you willing to pay to get what you NEED?
- What about what you WANT?

TIP: Finding balance between want and need

# Choosing a Plan: Key Questions and Considerations

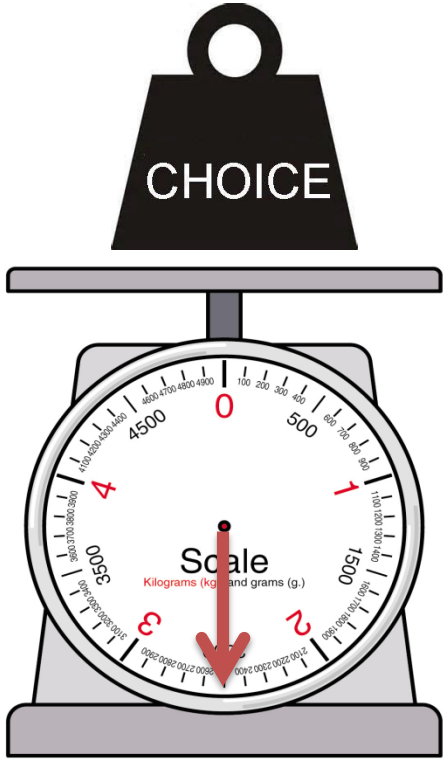
- What are the plan benefits?
  - Prescriptions?
  - Hospitalization?
  - Specialists?
- How much does it cost?
  - Monthly premium
  - Deductible, co-Insurance, & co-pays
  - In-network vs. out-of-network
- Disorder Specific
  - Is my treatment covered under the medical or pharmacy benefit?
  - Do I have a choice of more than one pharmacy provider?
  - Is my center in network?
  - Do I need a referral to see a specialist?
  - What services require prior authorization?
  - Is durable medical equipment covered?

# Network Considerations and Cost




Narrow Network
Lower Premium Cost

**Goal:**
Achieve balance between preference, choice, cost




Broad Network
Higher Premium Cost

# Issues to Consider
# Payer Techniques to Control Cost

- Narrowed Networks
- Out-of-Pocket Costs (OOP)
- Preferred Drug Lists/Restrictive Formularies/Exclude at Launch
- Specialty Tiers
- Step Therapy/Fail First
- Prior Authorization (PA)
- Rejection of 3rd party premium assistance
- Increased premiums
- Medical necessity provisions

# Patient Responsibility

- It's *your* responsibility to know your insurance policy
- Read your **policy** every year
- Open all mail received from your health plan
- Know your and your family's personal health needs & confirm they are covered
- Understanding your health plan is CRITICAL

TIP: Make an informed decision about your coverage options and know what has changed and what ***may*** change

# What Should I Lookout For?

- What services require prior authorization? Referrals?
- What is process?  How long does it take?
- What is appeal or medical exception process?
- How is my medication covered? Pharmacy vs medical
- Does my plan have a PBM?
- Does plan have a preferred provider for specialty pharmacy?
- Are there out of network benefits?  Penalties?

TIP: Verify plan benefits, document conversations (who, what, when), ask questions, get help

# New Administration

Administration Priorities

Congressional Agenda

Potential Impact

# How did we get here?

- **January:** Congress passes reconciliation instructions in budget resolution
- **March 6**: AHCA language released
- Goal for quick consideration and final vote on House floor by end of March
  - First vote pulled when there was insufficient support
- **April:** Negotiations continue, amendments drafted
- **May 4:** House passes AHCA: 217 to 213
- **June 22:** Senate releases the Better Care Reconciliation Act (BCRA)

# Concerning Policies

- Continuous coverage requirement undermines pre-existing condition protections
- Essential health benefits waiver undermines ban on lifetime and annual limits
- Patient and State Stability Fund could help with reinsurance but also facilitates implementation of high risk pools
- Medicaid reforms and expansion phase-out will jeopardize coverage

# Hurdles Ahead: Senate Bill

Primarily done by Senator McConnell's staff working to draft legislation

- "Gang of 12/13:" Members of Senate Leadership, HELP, Finance and Budget Committees

- No input from Democrats and little to no input from other Republicans

# Senate Bill: Worse than House

- Better Care Reconciliation Act of 2017 (BCRA)
- Senate must pass with majority vote
  - Partisan split even more narrow: 52 R to 48 D → can only lose 2 R's
  - Will all Democrats oppose the bill?
  - 19 Republican Senators come from states that expanded Medicaid

# What about Trump Administration?

- President ACA Executive Order signed on Day 1
  - Directs administration to ease the law's burdens through any legal means ("to the maximum extent permitted by law")
- HHS Secretary Price and CMS Administrator Verma have discretion to alter ACA regs → much more flexibility for states and issuers
  - Section 1332 Waivers re: private insurance
- Market Stabilization Rule Issued for 2018 Plan Year
  - Will this be enough to entice issuers to offer plans?
- What will happen to cost-sharing reductions payments?
- Recently suggested that Senate work to repeal now and replace later

# In the meantime . . .

- How many insurers offer plans on ACA marketplaces for 2018?  At what premium levels?
- Does Trump Administration continue to pay cost-sharing reductions payments?
- Continued fear what comes next and struggle with high premiums, deductibles and cost-sharing

# ACA Repeal and Replace

| | Current Law<br>ACA | House Bill:<br>AHCA | Senate Bill:<br>BCRA |
|---|---|---|---|
| **Individual Mandate** | Requires everyone to purchase health insurance or pay a penalty | ***Repeals*** individual mandate →New continuous coverage requirement | ***Repeals*** individual mandate → No coverage requirement |
| **Employer Mandate** | Requires large employers (50 or more employees) to offer coverage for their employees or face a penalty | ***Repeals*** employer mandate → No requirement to offer coverage | ***Repeals*** employer mandate → No requirement to offer coverage |
| **Young Adults** | Up to age 26 could stay on their parents plan | ***Unchanged*** | ***Unchanged*** |
| **Tax Credits** | Based on income, age, and location, up to 400% FPL | Based on ***age*** only | Based on age and income up to ***350%*** FPL |

# ACA Repeal and Replace

| | Current Law<br>ACA | House Bill:<br>AHCA | Senate Bill:<br>BCRA |
|---|---|---|---|
| **Cost-Sharing Subsidies** | Subsidies provided to the insurers to help some of the enrollee cover out-of-pocket costs: deductibles and co-pays | ***Subsidies end in 2020; administration may end earlier*** | ***Subsidies end in 2020; administration may end earlier*** |
| **Essential Health Benefits** | Plans have to cover 10 categories of services; patient protections only apply to EHBs | States can apply for ***waiver*** to define EHBs | States can apply for ***waiver*** to define EHBs |
| **Lifetime and annual caps** | Lifetime and annual caps banned for EHB services | State ***waiver*** of EHBs will undermine this protection | State ***waiver*** of EHBs will undermine this protection |
| **Out of pocket (OOP) expenses** | Max OOP for EHB services set - $7,150 for single and $14,300 for family (2017) | State ***waiver*** of EHBs will undermine this protection | State ***waiver*** of EHBs will undermine this protection |

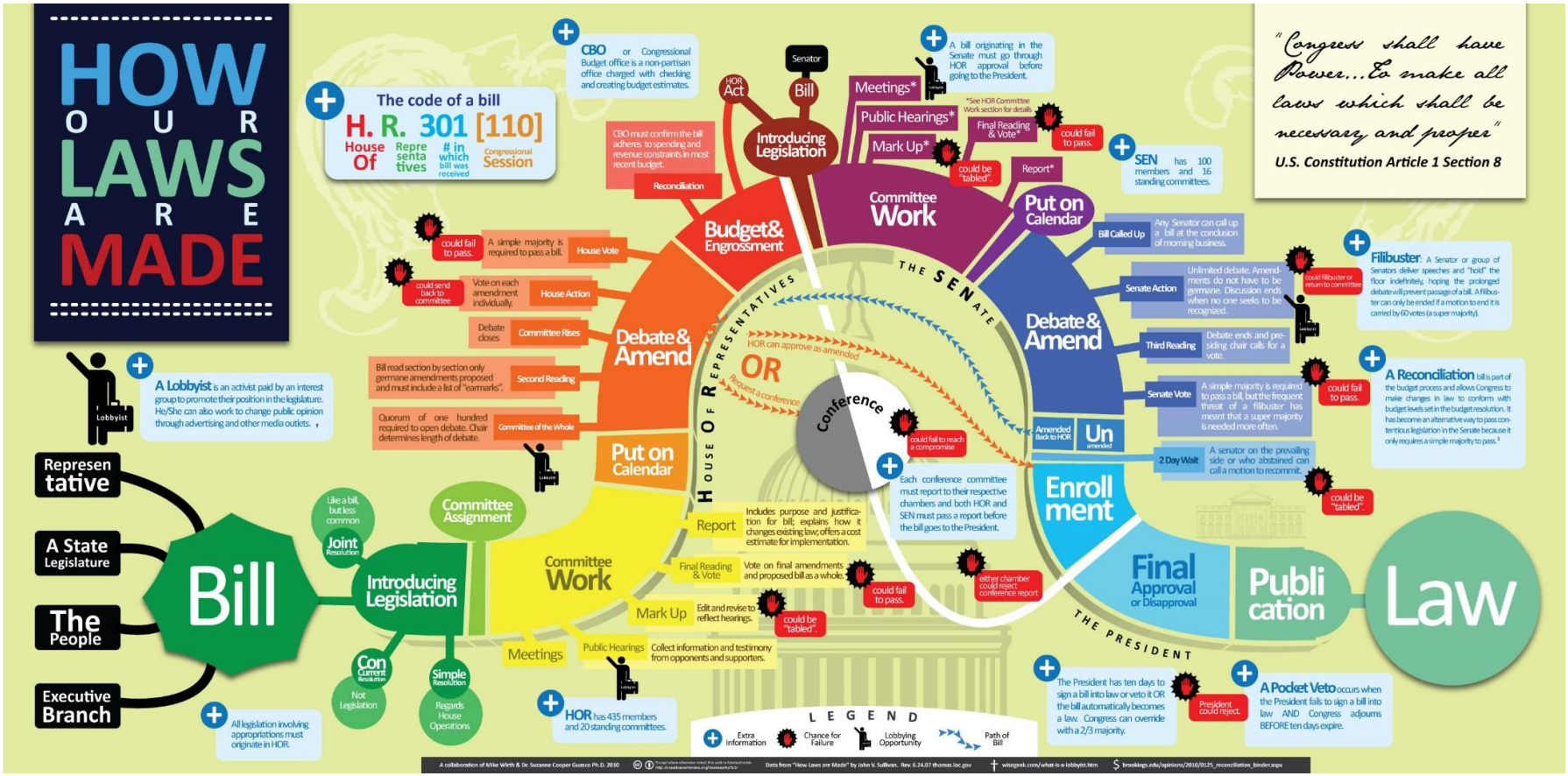
# How people pay for coverage? Subsidies and Tax Credits

- Federal health insurance subsides currently help ***most*** people pay for coverage (up to 400% FPL)
- Proposed changes
  - Health care would get less affordable for overwhelming majority of people who get assistance
  - ***ESPECIALLY*** people who make <400% of FPL, less healthy, and older

# Medicaid Reforms

- Fundamental restructuring of program financing and eligibility
- Medicaid expansion phased out
- Convert most federal Medicaid financing to per capita allotment starting in FY20-21
  - State option to receive block grant for either non-expansion adults and children or non-expansion adults only
- Significant cuts to Medicaid = ~ $880B in federal funding
- States encouraged to implement work requirements for many enrollees

# How a Bill Becomes a Law



# What should you do?

## Regarding Coverage

- Take Responsibility
  - Know your health care needs
  - READ your policy closely
  - Verify your covered benefits as well as plan requirements related to prior authorizations and referrals

## Regarding the Repeal and Replace

- Advocate:
  - Stay informed - What are the changes being discussed? How will they impact you and your family
  - Get Involved! Understand the legislative process
  - Contact your Senators and tell your story – how has the ACA (and the patient protections included) benefitted you/ your family

# What to Remember

- YOU can positively impact the future of your community and others with rare diseases with your advocacy efforts
- Education of public officials and policy-makers is crucial to ongoing efforts
- Education is a 12 – month process – don't just focus on the Legislative Session
- ***A basic understanding of the process ensures that issues do not slip through the cracks***
- Don't just raise problems….bring solutions
- You are never too old or too young to be an advocate!!

# Questions?