

Insurance and Financial Considerations and Legislative Advocacy

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Available Coverage

- Employer group coverage
 - Subject to HIPAA protections
 - If >20 employees, subject to COBRA
 - 39 States have Mini-COBRA
 - If employee group is small,
 - Subject to HIPAA Guaranteed Issue
- Private, non-group coverage
 - HIPAA Guaranteed Issue if federally eligible
- Public plans

Group Plan HIPAA Protections

- 12 months of continuous, creditable coverage
 - 18 months if late enrollee
- Group health plan cannot exclude coverage for a preexisting condition, regardless of your health condition

Preexisting Condition Exclusions

- If no previous creditable coverage
 - Group plan can exclude coverage for a preexisting condition
- If medical advice or treatment for the condition was received during the 6 months immediately preceding health plan enrollment date

Continuous, Creditable Coverage

- Includes most kinds of health benefits
- Does *not* include coverage before a "significant break" in coverage (≥ 63 days) in coverage

HIPAA Nondiscrimination Provisions

HIPAA nondiscrimination provisions prohibit a group health plan from basing *eligibility* or *premiums* on any of 8 health factors

- | | |
|--------------------------|---|
| • Health status | • Medical history |
| • Genetic information | • Evidence of insurability |
| • Claims experience | • Disability |
| • Receipt of health care | • Medical condition <ul style="list-style-type: none">- Includes both physical & mental illness |



COBRA

- Coverage available through COBRA
 - Employee qualifies if employment terminates for other than gross misconduct
 - Non-employee qualifying event
 - Spouse of employee who becomes eligible for Medicare
 - Divorce or legal separation from covered spouse
 - Death of covered spouse
 - Loss of dependent child status under plan rules
 - American Recovery and Reinvestment Act (ARRA) expansion: 65% COBRA premium subsidy for first 9 months



Private Non-Group Insurance

- Coverage sold by health insurance issuers or HMOs to individuals who are not part of a group health plan
- Might be through an association or other group, such as college students or self-employed individuals
- HIPAA provides guaranteed renewability and provides guaranteed issue to HIPAA-eligible individuals



HIPAA Federally Eligible

- At least 18 months of continuous creditable coverage
- Most recent coverage under a group plan
- Not eligible for another group health plan
- Most recent coverage not cancelled due to nonpayment of premiums or fraud
- Not eligible for Medicare or Medicaid
- COBRA or state continuation coverage exhausted
- Did not accept a conversion or short-term, limited-duration policy

Bleeding Disorders Wish List

- Increase or eliminate lifetime caps
- No preexisting condition exclusions
- Access to
 - Medically prescribed and cost-efficient health care
 - Exact brand and quantity of clotting factor prescribed by physician
 - Other necessary ancillary services necessary for optimum care
 - Providers who follow minimum standards of care in handling and delivery of factor and other healthcare services

Assessing Your Choices

- What type of plans are available?
- Which plans are the most affordable?
- Do we qualify for Medicaid or a state program?
- Do my children qualify for SCHIP?
- Which programs or plans best meet my needs and the needs of my family?

Know Your Plan: Coverage

- Factor coverage
 - Medical or pharmacy benefit?
- Is there an annual deductible?
 - Which medical and pharmacy costs apply?
- Is there a lifetime benefit cap?
 - Which medical and pharmacy costs apply?
- Is there a maximum out-of-pocket limit?
 - Which medical and pharmacy costs apply?



Know Your Plan: Cost Sharing

- Copays and/or coinsurance for
 - Doctor's office visits?
 - Preventative care?
 - Diagnostic Lab and x-ray tests?
 - Preventative lab and x-ray tests?
 - Inpatient stays and professional services?
 - Hospital outpatient/ambulatory surgical services?



Know Your Plan: Providers

- Hemophilia treatment centers (HTCs) and/or other providers in the network?
 - Physician?
 - Specialists?
 - Pharmacies?
- Emergency room visits covered?
 - How is "emergency" defined?



Know Your Plan: Limits/Exclusions

- Limits to the number of covered visits for certain services?
- Dollar limits for certain services?
- What conditions and services are excluded?
- Automatically renewable?
- Waiting period before coverage begins?



Know Your Plan: Choices

- What are my choices?
 - HMO, PPO, traditional, HSA?
 - Which works better for my family?
- Ask to see the Master Policy
- Ask for sample claims runs for each plan



Potential Problems

- Tiered drug plans
- Specialty injectables benefit changes
 - Separate out-of-pocket maximums
 - Separate caps
- Additional restrictions on provider networks, especially pharmacy/home health providers
- Self-funded plans cutting or limiting expensive benefits



Healthcare Reform *Possibilities*

- No lifetime caps
- No preexisting condition exclusions
- Public health insurance option
- Expansion of public programs
- Other accessibility and affordability improvements

National Hemophilia Foundation (NHF) Advocacy

- Educate elected officials and others in government
- Raise awareness of bleeding disorders
- Work to protect individuals from discrimination
- Work to ensure full access to high-quality care
- Work closely with chapters, associations, and other key stakeholder groups to address community needs at the state and local levels

NHF Advocacy Priorities: Federal Issues

- Increase or eliminate lifetime caps
- Access and funding for HTC's
- Monitor federal issues
 - Healthcare reform, Medicaid/SCHIP, Medicare/Medigap, comparative effectiveness research, biologics/biosimilars

NHF Advocacy: Federal Agencies Monitored

- Centers for Disease Control
- Food and Drug Administration
 - Blood Products Advisory Committee
 - Transmissible Spongiform Encephalopathies Advisory Committee
- Health and Human Services
 - Center for Medicare and Medicaid Services (CMS)
 - Health Resources and Services Administration (HRSA)
 - Advisory Committee for Blood Safety and Availability
- National Institutes of Health

**NHF Advocacy:
Coalitions**


- Lifetime Caps Coalition
- Plasma Users Group
- Hemophilia coalitions
- CDC Coalition
- NHLBI Constituency Group
- National Health Council

**NHF Advocacy:
Washington Days**


- An annual event
- Opportunity to come together to discuss key issues and learn about advocacy
- Community members meet with elected officials, and put a face on bleeding and clotting disorders

**NHF Chapter/State
Advocacy**


- Priorities
 - Access issues
 - Preferred drug lists/sole source
 - Specialty pharmacy standards
 - Access to hemophilia treatment centers
 - Advisory boards

 **NHF Chapter/State Advocacy**

- Assists chapters in working with
 - State Medicaid agencies
 - State legislators
 - State insurance regulators
- Consults, advocates, educates
 - State-specific issues
 - National issues

 **Reimbursement 360**

- Program to address all aspects of access to reimbursement through
 - Payer education
 - Presentations to private and government payers
 - Consumer education and information
 - Education sessions at NHF and chapter meetings
 - Provider education
 - Sessions specifically geared toward providers at NHF and chapter meetings and workshops

 **HANDI**

- NHF's Resource Center for Coagulation Disorders
 - Provide quality, educational publications
 - Pamphlets, textbooks, CD-ROMS, and videos
 - Travel to NHF meetings to answer questions and provide materials
 - **HANDI@hemophilia.org**



Resources

- NHF
 - www.hemophilia.org
- Kaiser Family Foundation - All healthcare issues
 - www.kff.org
- Families USA - All healthcare issues
 - www.familiesusa.org
- Thomas - Congressional Web site
 - www.thomas.gov
