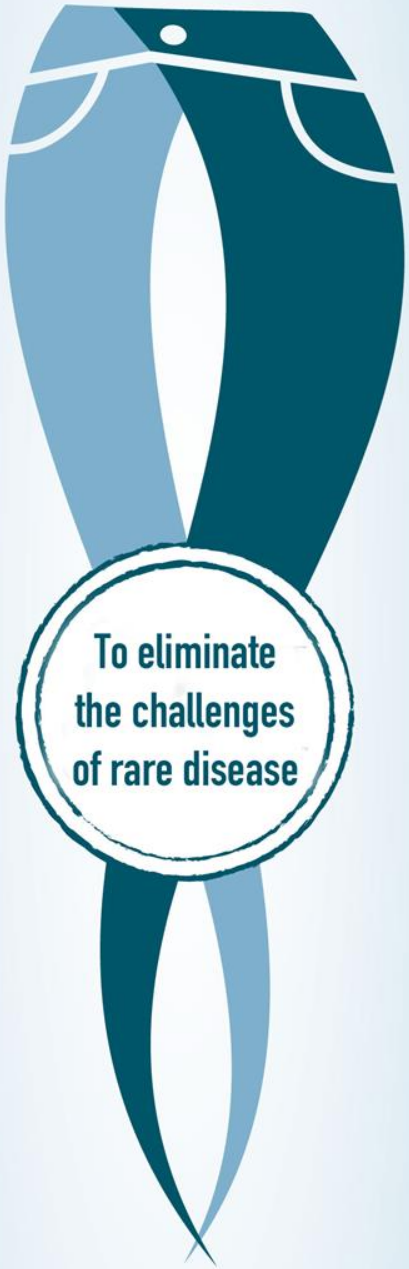

Global Genes™
Allies in Rare Disease

Navigating Health Insurance Issues, Part 2

June 18, 2014

Sponsored by:

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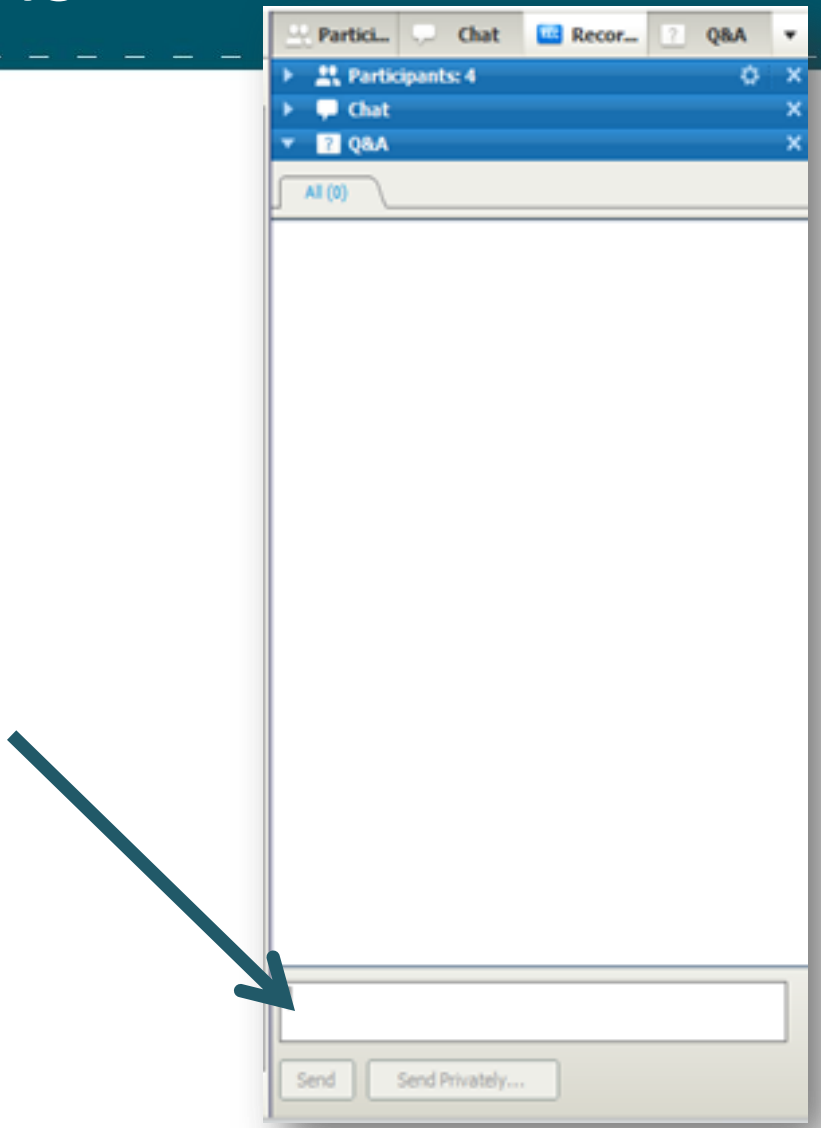
Submit Your Questions

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 on the right hand side & direct your questions to the Global Genes representative (or Host), Katie Mastro

Feel free to submit questions throughout the presentation



Meet Today's Panelists:

Julie Raskin
Congenital Hyperinsulinism International

Stephanie Bozarth
National MPS Society

Pam King
Global Patient Strategies

Moderator:

Jennifer Bernstein
Horizon Government Affairs

Accessing Specialty Rare Disease Care Despite Health Insurance Plan Limitations

Julie Raskin
Executive Director

When Elements of Care Aren't Covered

- Engage your rare disease patient advocacy organization.
- Maintain close relationships with your doctors' staff.
- Remember, insurance plan personnel are people.
- Connect with insurance plan decision makers.
- Stay calm when there is a sudden change in a plan or new people involved in administering a plan.
- HR personnel on an employee plan can help.
- Accept positive advice from other patients who have successfully traveled the same road.
- Hopefully, "no" is just part of the process of getting to "yes."
- Leave behind anger and "principles."
- If there is one, engage with biotech or pharma company developing or producing the drug.

Other Steps to Get to a Yes

- Be persistent. Case managers, medical directors, and others in the insurance world can be very busy. Call or email frequently until response is elicited. Continue to rely on the specialist's office, physician, and the patient advocacy organization for support.
- When necessary, contact local and state officials. Share your story. Let the insurance company know you will be contacting officials.
- If necessary, talk to the press. Most towns have local blogs or newspapers. Get in touch and share your story. Tell the insurance company you will be contacting the press.

Admittance to an Out Of Network Hospital that can Treat your Rare Disease

- **Letter of Medical Necessity** from the referring physician or the attending at the accepting institution is often needed.
- **Peer to Peer Review** may be necessary. Dr. who is making the case for the transfer will present evidence that the patient must be admitted to save the patient's life, reduce risk of adverse effects, or improve the odds of measurable and significant quality of life issues.
- For **Medicaid plans**, insurance plan might request 3 opinions from peers about ability to handle case in state.
- **Letter from patient advocacy organization** to medical director or physician making the decision about the transfer is a good idea. Letter needs to be very compelling, specific, and persuasive.

Outpatient Office Visits to Out-of-Network Clinic or Hospital

- Work with your physicians and your plan case manager on this.
- **Prior Authorization** will be necessary.
- **Clinical notes** from referring physician may be necessary and **Peer to Peer Review**.
- Try to get authorization for a series of visits.
- You may have to appeal so get started as soon as you can.
- Local referring doctor usually has to be involved in appeal.
- Include **authorization for labs** with your request.
- Letter from patient advocacy organization to the case manager, medical director or physician making the decision about out-of-network visits to clinic or hospital is suggested.

Getting a Medication Covered That Is Not In The Formulary

- A **Formulary Exception Request** is needed when there is only one drug in the plan approved for the condition but it is not indicated for the patient and another drug is.
- Specialist doctor writes this letter and must include information proving that the requested medication is life sustaining or significantly improves quality of life.
- Patient advocacy organization can also write to medical director or physician making the decision about the **Formulary Exception.**
- When medication is prescribed **Off Label** the **Formulary Exception Request** is still made by specialist doctor. The specialist doctor should provide clinical information proving that off label med is needed.
- Drug company may have patient advocates who can help.

Getting the Correct Dose of Medication

- **Dispensing Limit Prior Authorization Request**
- Specialist doctor will submit this request to the insurance plan case manager.
- More frequent trips to the pharmacy may be necessary.
- Letter from patient advocacy organization to the case manager, medical director or physician making the case for following the prescribing doctors instructions about dose.

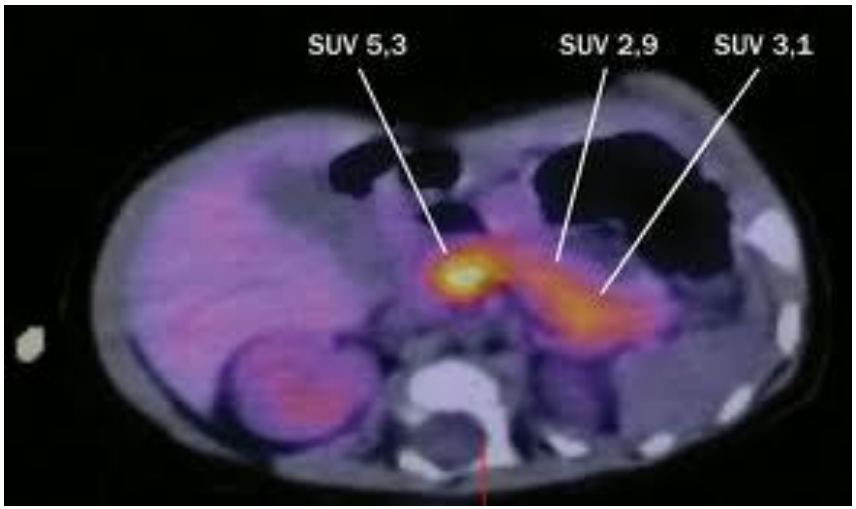
Devices and Supplies

Common supplies and devices used for rare diseases sometimes pose a problem:

- A **Letter of Medical Necessity** is often needed. Must have compelling reasons for needing these. This is often an area where specialist physician support is **extremely important**.
- Can be complicated because devices and supplies are contracted through durable medical equipment companies, not a pharmacy. A whole new team, in addition to those dealing with medication, get involved. Sometimes there are different suppliers with different processes.
- As always, a strongly worded letter from the patient advocacy organization helps.
- Even when supplies are granted, there are often limits. Sometimes these limits need to be exceeded for a patient. Exceeding the limit must be included in the **Letter of Medical Necessity**.

Costs Associated with Experimental Treatment

- Experimental treatment is usually covered by the treating hospital.
- Sometimes patients have issues with costs that are associated with the treatment but not considered part of the treatment. For instance, there may be anesthesia involved.
- Find out in advance which costs the hospital will expect the insurance plan to pay prior to the treatment so that agreements can be made for the insurance plan to cover these additional costs.
- **Letter of Medical Necessity** may be required.



Thank you from CHI!

Appealing a Limited Provider Network

Stephanie Bozarth,

Vice President

What is a Provider Network?

- A network of providers that have a contract with an insurance plan which set the reimbursement, pricing, and range of coverage.
- A LIMITED provider network has a smaller subset of providers within the overall medical network.
- Members covered under a LIMITED network generally must receive services from a provider within this identified subset.

Challenges of Limited, Narrow Provider Networks

- Limited access to specialists for diagnosis and treatment of specific rare diseases
- Out-of-network increase in financial responsibility to receive specialized care
- Out-of-network specialist co payments & charges may not count toward max out of pocket spending
- Rare diseases have few therapeutic options which are provided by specific specialists

High out of pocket cost are a potential barrier to diagnosis, symptom management, and treatment

Potential Costly Problems of Limited Networks

- Misdiagnosis and treatment
- More costly emergency room visits
- Less optimal disease management
- Medical and surgical interventions that may do more harm and cause further complications

Optimal Specialty Care and best practices correlate to educated patients/caregivers and optimal quality of life outcomes.

Why the Trend to Limited Provider Networks?

- Insurers leverage more favorable reimbursement from a selective In Network provider by promising more patients due to narrow network.
- Insurer may simply identify its lowest cost providers and include only those providers in its limited network.
- While limited networks may mitigate premium increases and drive quality in the private marketplace, they also have the potential to limit a consumer's choice of, and access to, providers.

Stakeholders should monitor the impact of these networks and work together to find the right balance among cost, quality, access, and choice.

Rare Disease Specialty Network

Orthopedic Surgery

Anesthesiology, Radiology, Nuclear Medicine

A.I. Dupont Hospital for Children

Ophthalmology

Children's National Specialist of VA

Pulmonology

Children's National Health System

Annabelle
8 years old
Morquio Syndrome

Home Health

Quality Health Services, LLC

ENT

Children's National Specialist of VA

Physical & Occupational Therapy

Specialty Pharmacy

CVS Caremark

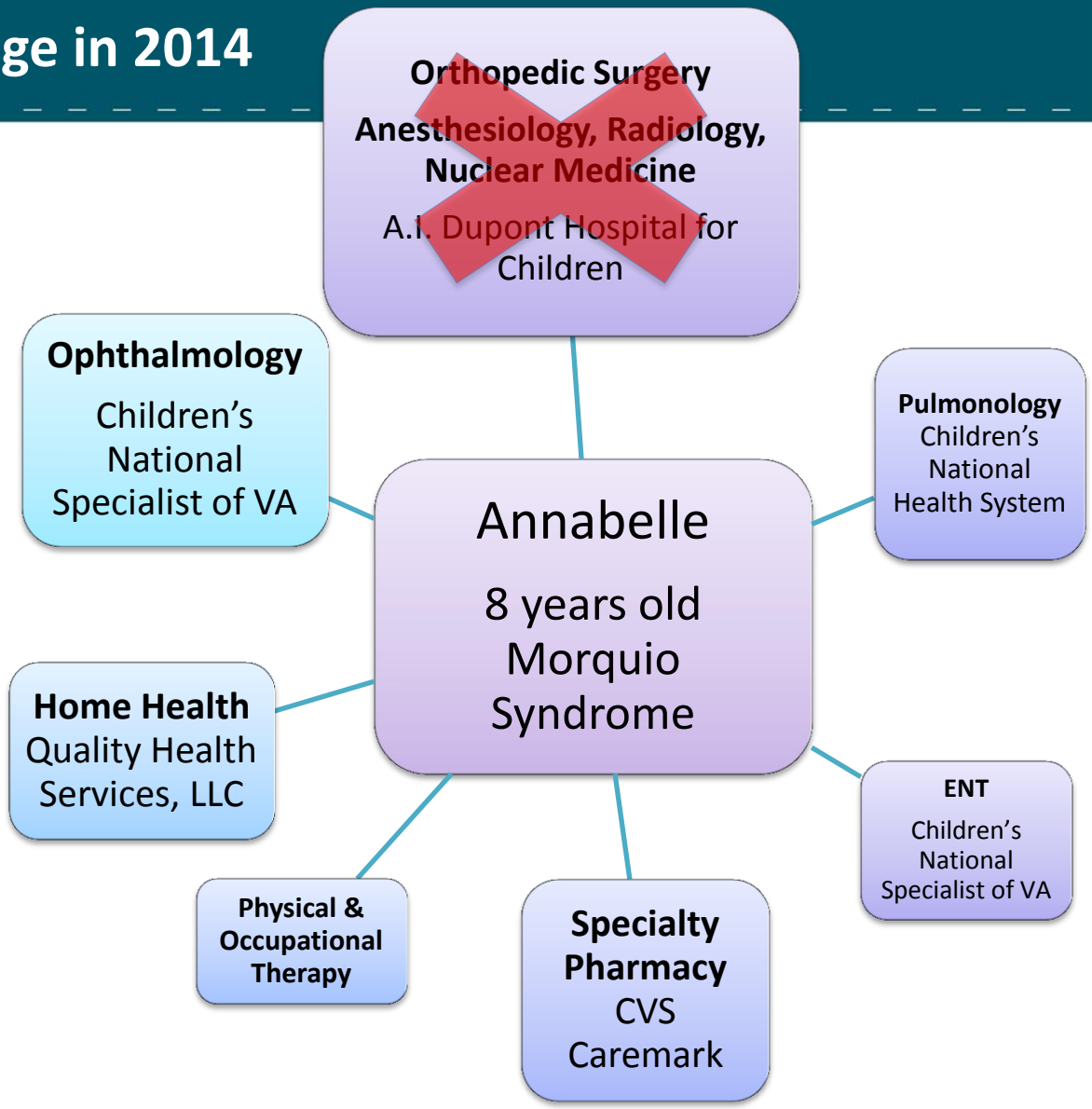
United Healthcare Limited
Provider Network Change in 2014

In April 2014, A.I. Dupont Hosptial contract with UHC was terminated.

The hospital and Orthopedic Surgeon specialize in skeletal dysplasia and are experienced with Morquio patients. Without surgical intervention, she will ultimately lose the ability to walk among many other life threatening possibilities.

Out of Network care will potentially cost 5-6 times as much as In Network covered provider care.

Deductible and out of pocket maximums are significantly higher.



Appealing the Limited Network

- Contact your insurer and inquire about any programs that will provide Continuity of Care Coverage or Gap Network Exceptions
  - Enroll or start the process to appeal to those programs
- File a letter of concern/complaint regarding how the limited network is impacting the continuity of care, why it is cost effective to allow specialty care, and why it is the morally right decision.
- Additional Letters to support your claim for Continuity of Care Coverage
  - Disease specific advocacy group letter
  - Physician, Specialist, and or Geneticist letter

Advice & Tips

- Keep it in perspective
  - What is the worst case scenario in terms of cost?
- Engage your network of providers, employee human resources, local media, and/or advocacy groups to help you advocate on your behalf.
- Identify the “Gate Keepers” within your insurance plan and your employee human resources. Appeal directly to them.
- If all else fails, contact the provider directly to negotiate a Self Pay Rate.

Appealing Treatment Regimen Coverage Restrictions and Denials

Pam King,
Global Patient Strategies

Restrictions Facing the HAEA Community

- Step therapy - failing androgens before access to newer treatments
- Quantity and dosing limits
- Discrepancy/plan changes (major medical to pharmacy coverage) - exclusions

Appealing Restrictions and Denials

- Work with your patient organization
- Work with your provider
- Work with manufacturer's patient support team

HAEA's Advocacy Effort to Improve Medicaid Coverage

- Identified which states had scheduled HAE class review
- Gather policy information for that state
- Reach out to manufacturers to understand potential issues and changes
- Sign up for public testimony
- Identify physician in that state for testimony/letter
- Letter from association

HAEA: Working with Commercial Plans

- Gather specifics for the patient's case
- Gather policy information for that plan
- Reach out to manufacturers to understand potential plan issues
- Set up call with health plan medical director
- Medical Advisory Board member call with plan
- Accompany with letter or email

Media Campaigns

- Last resort
- Work with patient to craft story/background
- Communicate with manufacturer to identify resources/agency support that can assist story pitching
- Work with local papers/news stations
- Letter or visit to local congressman

Final Tips

Utilize Your Resources:

- Patient organization
- Provider
- Manufacturer support program

Closing Remarks

Next Upcoming RARE Webinar

Using Successful Online Fundraising Strategies

July 30, 2014
10:00 am PST / 1:00 pm EST

Register today at
http://globalgenes.org/using-successful-online-fundraising-strategies/