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Committee on ALS: Accelerating Treatments and Improving Quality of Life

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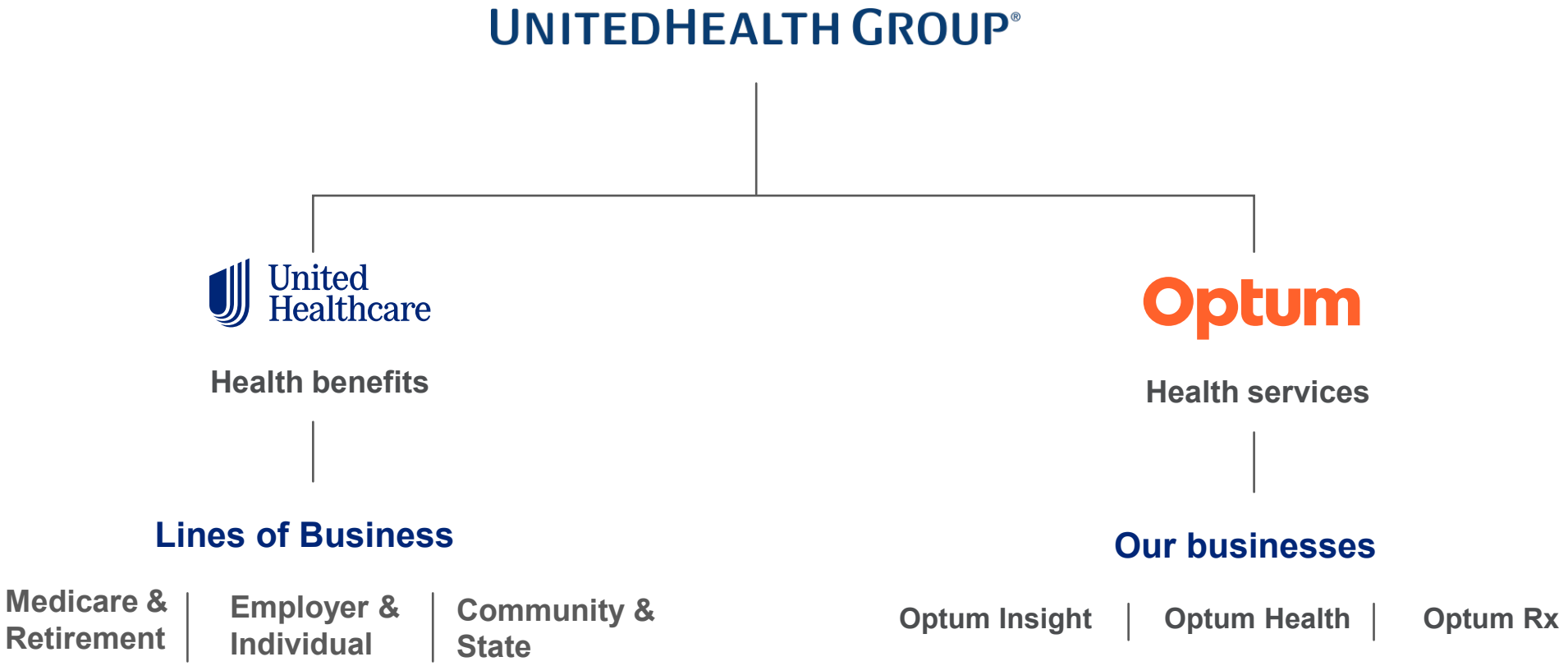
Who Are We



Health Insurance Coverage – Care Considerations

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Private Health Insurance and ALS

ALS diagnosis creates Medicare eligibility

- If employed and have employer-based coverage – need to consider family coverage if no longer able to work
- Option for “straight” Medicare – Parts A, B and D, vs Medicare Advantage – Part C
- Medicare Advantage plans may offer additional benefits

Navigating “the system” is complicated - many plans will offer care management to help although rare to find specialists in ALS

New drugs are expensive – medical policy will usually be approved if meet FDA criteria

- Copays/coinsurance prohibitively expensive – need to find ways for patients/families to pay for it – pharmaceutical programs, grants
- Consider outcome measurement and value-based care contracts with pharmaceutical companies
- Need to increase and simplify enrollment in clinical trials

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United Healthcare/Optum Experience

Very hard to find data

Estimate 12 cases per 100,000 members in Optum population from data mining - in line with national estimates*

6800 patients out of 55 million total population

Care management available through general high-risk programs

Specialized care management available through rare diseases specialty pharmacy for individuals in certain new medications

Specialty medication market anticipated to grow

*as calculated 6/2023

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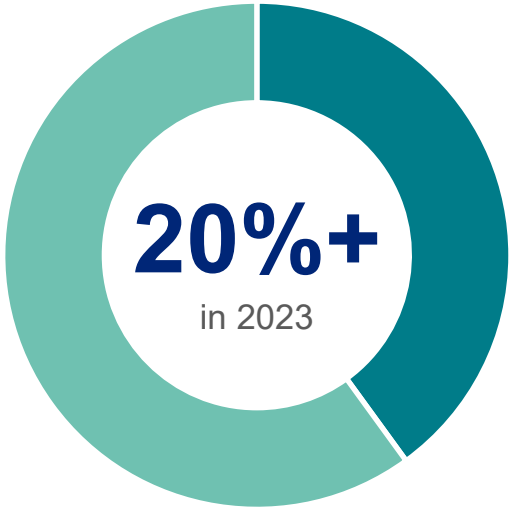
The rise of rare disease therapies

Rare, orphan, cell, and gene therapies are rapidly emerging as a distinct class of therapies — posing unprecedented challenges

There are more than 1,600 rare disease therapies in the development pipeline[1], enabled by **advances in technology** and **special regulatory pathways**

They hold **life-changing promise** for people living with rare disease, and some offer potential to **reduce the total costs of care**



Rare, cell, and gene therapies are expected to make up more than **20 percent of total U.S. drug spend** in 2023 and grow by 15% every year through 2028.[2]

[1]**Source:** EvaluatePharma

[2]**Source:** IQVIA, Azoth Analytics

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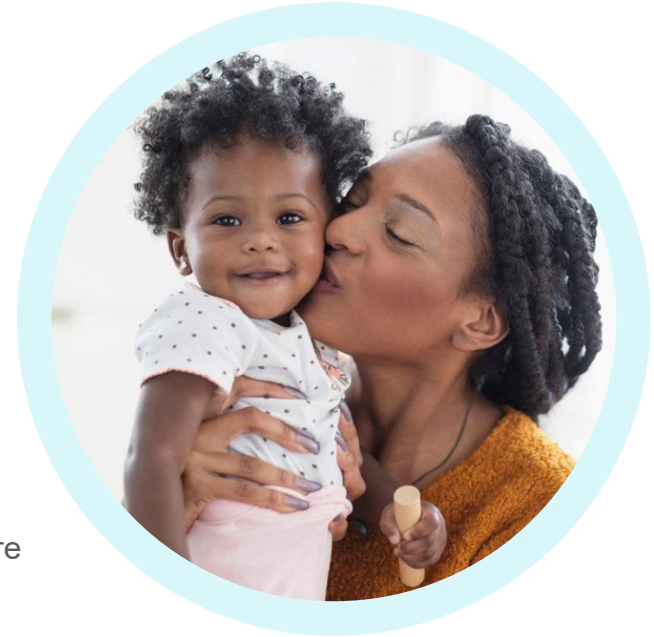
The partner for managing the new frontier of health care

Purpose-built to solve the unique challenges of rare disease



Optum Frontier Therapies

An independent, mission-driven health care services business continually evolving capabilities to better serve rare disease stakeholders: patients and caregivers, physicians and offices, pharmaceutical partners, and payers

- Specialty pharmacy care services, optimized through a single point of contact model, solely focused on people living with rare diseases
- Orphan, rare disease, cell & gene therapy health care services powered by holistic, patient-first care and clinical expertise to streamline access and optimize outcomes
- Commercial services designed to proactively address challenges in the marketplace
- Integrated, precision focused distribution to eliminate therapy delays and reduce waste within the ecosystem

It is our mission to create access to therapies at the frontier of health care and to help all people, no matter how unique, access a better tomorrow.

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Recommendations

Find ways to enable caregivers – consider allowing them to be certified as home health aids

Encourage enrollment in clinical trials – look at pediatric oncology as a model

Be BOLD – small changes are not going to achieve the target