



The Pacific Northwest Chapter of the  
International Society of  
Certified Employee Benefit Specialists



## Rare Disease Therapies Over \$500,000: Plan Sponsors Take Warning!

Thursday, June 6, 2019 | 11:45 – 1:00 Pacific

Via Webinar

No Cost

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It has been several years since the removal of annual and lifetime dollar limits under the Affordable Care Act's requirements. Health systems and pharmaceutical manufacturers have uncovered a means to fund therapies and treatment for rare disease previously not treatable or financially viable. While their outcomes are life preserving, their costs are tremendous – often in excess of several hundreds of thousands of dollars, if not millions, which can potentially be ongoing each year. Most often, these therapies treat dependent children where wellness initiatives do not have an impact. Their rarity stymies purchasing programs and effective PPO discounting. The financial risks to health plan sponsors, particularly those that self-insure, are significant – impacting not just the plan, but the organization as well. Aside from the Human Resources and Benefits divisions of a company, the CFO and Finance department also need to be aware of the potential severity of a sudden, significant claimant. If it is an ongoing annual therapy, an unreserved future liability can be several millions of dollars – unlike anything previously seen in an active employee health plan. Expenses as high as \$5 million or more have been recorded. Risk management in the form of stop loss is being tested as never before, and increasingly applicable to plan sponsors as large as 20,000 employees or more.

### Top Take Aways

- Awareness of the financial severity of these claimants; how they are congenital and not impacted by wellness programs; and the Wall Street and “big business” objectives driving these prices and lack of effective PPO pricing.
- Understanding of risk management approaches, including medical stop loss – even for plan sponsors traditionally not covered. Recent results from the *2018 Aegis Risk Medical Stop Loss Premium Survey* will be incorporated.
- Discussion of potential pitfalls in securing stop loss coverage due to these claimants, such as renewal lasers and non-coverage once a claimant is incurred.

**Speakers:** Ryan Siemers, CEBS | Principal | Aegis Risk LLC | Alexandria, VA

Ryan Siemers is a Principal at Aegis Risk LLC, a consulting firm and brokerage focused on medical stop loss and the financial management of catastrophic medical claimants. Since founding Aegis Risk in 2005, Ryan has provided numerous medical stop loss analyses for private and public employers throughout the United States. As a recognized expert on medical stop loss, he is frequently quoted in national trade journals and regularly speaks to audiences in the employee benefits, risk management and health care arenas. He is the author of the annual Aegis Risk Medical Stop Loss Premium Survey, done in conjunction with the International Society of Certified Employee Benefits Specialists (ISCEBS). With over 25 years of employee benefits experience, Ryan earlier served as a health and welfare benefits consultant and a financial underwriter prior to forming Aegis Risk. He is a Certified Employee Benefits Specialist (CEBS) and the current Secretary/Treasurer of the International Society of Certified Employee Benefit Specialists Governing Council.

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