

Ongoing Medication Recall Ignites Formation of a New NonProfit: HypoPara Support & Advocacy Inc

Massachusetts, Boston, Sep 20, 2021 ([IssueWire.com](https://www.issuewire.com)) - Every morning, Ryan Polly wakes up and immediately takes a dose of calcium and vitamin D before getting out of bed. For Ryan, like many people who suffer from hypoparathyroidism, taking calcium isn't to help his bones but rather to ensure his nervous system is able to function. Without this morning dose of calcium, Ryan would likely be unable to get out of bed as his body would seize up, preventing him from moving freely and causing significant pain.

As the day progresses, Ryan continues to provide his body with calcium and a cocktail of other supplements and injections in order to function. Before going to sleep at night, he takes more calcium. Often, he gets up in the middle of the night to take even more. Calcium is so important for Ryan that he has bottles scattered throughout his house, in his briefcase, in his car, and in his desk at work. His administrative assistant even has a bottle, just in case of an emergency. Ryan's life revolves around a daily medication routine and a tightly controlled schedule to ensure he doesn't miss a dose. Without calcium, this could lead to serious complications including the possibility of cardiac arrest

Ryan is one of about 70,000 people in the United States who suffer from hypoparathyroidism, a rare disease that impacts the body's ability to regulate calcium. In most cases, hypoparathyroidism is acquired following neck surgery (such as a thyroid removal) due to the accidental removal or damage of the tiny parathyroid glands that sit behind the thyroid gland.

The parathyroid glands release parathyroid hormone (PTH), which is critical to the process that allows calcium to be removed from and returned to the bones as needed. Without PTH, the body is unable to remove calcium from the bones, which causes blood levels of calcium to become dangerously low. This inadequate calcium regulation leads to a range of symptoms, including tingling and numbness, tetany, memory issues, cognitive changes, and serious complications such as throat closure, seizures, and cardiac arrest.

Currently, hypoparathyroidism is the only endocrine condition without an available hormone replacement. Without a PTH replacement medication, people with hypoparathyroidism often need to take high doses of supplemental calcium in order to function. Unfortunately, this high dosing wreaks havoc on the body. Without PTH, the kidneys are unable to filter calcium adequately. Over time, the supplemental calcium needed for functioning can cause kidney stones or other calcifications and can cause permanent damage to the kidneys.

In the fall of 2019, the only FDA-approved PTH replacement to treat hypoparathyroidism, Natpara, was abruptly [recalled](#) due to a potential concern that small particles of the rubber stopper in the injection pen could clog the needle and reduce the medication provided. Natpara was used to treat those who were the least stable or who could not adequately absorb oral calcium, which made its recall all the more painful for this community.

Since the recall, more than 2,500 people have lost access to this extremely important medication. While there have been updates along the way, the HypoPara community continues to live without a clear indication of when this medication will once again be available. Today, Natpara remains recalled, and while Takeda recently submitted a proposed fix to the FDA, they are waiting on the FDA to determine whether they will accept or reject the proposal, a process that can take many months.

Frustrated by inaction and lack of information, several long-term hypoparathyroidism patients formed [HypoPara Support & Advocacy Inc](#) to raise awareness, advocate, and do what they could to improve the lives of those suffering from hypoparathyroidism.

“It is absolutely unacceptable that we’ve been without medication for nearly two years,” says Ryan Polly, the Founder & President of HypoPara Support & Advocacy Inc, a Boston-based non-profit, “there are major gaps in the treatment of rare disease. People are suffering, and that needs to stop.

“Since its incorporation in mid-May, the organization has made progress toward its goals. They’ve built relationships with several other rare disease organizations and speak frequently with Takeda to urge an accelerated return of Natpara to market. While their biggest plans and projects are still in the development phase, the organization is proud of what they’ve accomplished so far.

“We are a small community,” says Polly, “but we are strong, and we are not alone. Millions of people suffer from a rare disease. By working together, we can not only improve the lives of our own community members but can also help ensure anyone suffering from a rare disease has treatment options and access to affordable and quality care.”

To learn more about HypoPara Support & Advocacy Inc, visit:

www.hypoparasupport.org

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