



Hypoparathyroidism affects

80,000

patients in the
United States

Voices of Hypopara Survey Fact Sheet

What is Hypoparathyroidism?

Hypoparathyroidism (hypopara or HP) is a rare endocrine disorder characterized by insufficient levels of parathyroid hormone (PTH), resulting in low calcium and elevated phosphate levels in the blood. Hypopara affects approximately 80,000 in the United States (U.S.) alone and 200,000 patients in the U.S., Europe, Japan and South Korea. The majority develop the disorder following damage or accidental removal of the parathyroid glands during thyroid (neck) surgery. This condition can also be inherited or associated with other disorders.

With hypopara, patients often experience decreased quality of life. In the short term, symptoms include weakness, severe muscle cramps (tetany), abnormal sensations such as tingling, burning and numbness (paresthesia), memory loss, impaired judgment and headache. Over the long term, this complex disorder can cause calcium deposits in the kidney, brain, blood vessels, eye, and other soft tissues, increasing risk of kidney disease and other major complications.

Voices of Hypopara Patient Survey

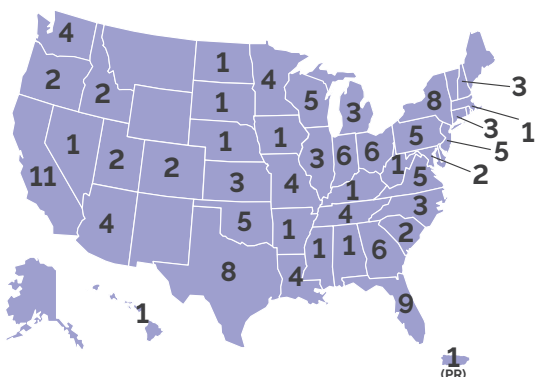
The Voices of Hypopara survey was conducted by the HypoPARAthyroidism Association to highlight the experiences of patients in the U.S. who are living with hypopara.

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Because the symptoms aren't easy to see I often feel like no one understands. I feel very isolated.

-Voices of Hypopara survey participant

Participants Across the United States (N=146)



About the Survey

- 146** patients with hypopara participated in the survey
- 89%** were women and the average age was 51 years
- 60%** have lived with hypopara for 5 years or longer

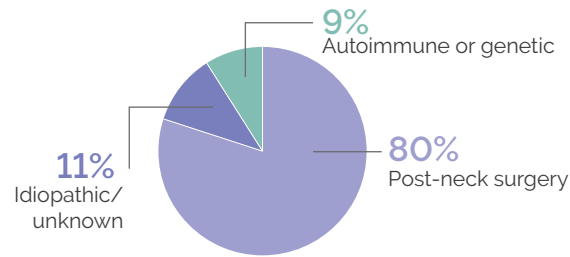


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June 2020

Survey Highlights: Complex Patient Journey

Causes of hypopara



Delays to getting diagnosed with hypopara (N=146)

For half of the participants, more than five physician visits

For a quarter of the participants, more than a year

For approximately 10% of participants, over a decade to be properly diagnosed

Managing Calcium Levels Remains A Key Challenge

Patients manage an impending crash in various ways, including taking supplements (93%), eating calcium rich foods (45%) and in some cases, seeking medical attention (31%)



A **calcium crash** is a potentially life-threatening decrease in calcium levels that can cause an inability to speak or breathe, involuntary or painful muscle spasms, and even seizures.

Calcium Crashes

of all patients surveyed...

69%

experienced them at least once in the past year

43%

experienced them monthly or weekly

4%

experienced them daily

Current Standard of Care Viewed as Burdensome

- Nearly all patients received standard of care (calcium and/or active vitamin D) and the majority (69%) felt their treatment was moderately to extremely burdensome
- In addition to calcium and/or active vitamin D, some participants were taking PTH replacement, investigational or other treatments to manage their symptoms
 - Others included phosphate binders (phosphate lowering drugs), magnesium supplements and thiazide diuretics
- Almost all participants changed their medication regimens at some point, with 61% changing more than 5 times since being diagnosed; the frequency of medication changes reflects patients' struggles to manage hypocalcemic events/calcium crashes with available therapies



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Serious Symptoms or Complications May Require Emergency Care

- Approximately 42% of participants (n=62) visited an ER and/or urgent care facility in the last year to address their symptoms; half visited 2 to 4 times, and another 18% visited even more often in the past year
- Serious calcium crash episodes may require IV infusions of calcium in an ER or urgent care setting
 - 63% of those who visited the ER and/or urgent care received IV calcium to manage their calcium crash; a quarter of these patients received IV calcium 5 or more times in the past year

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I have no choice. I need the calcium IV or I can't function. I have to go no matter what.
I need my calcium.

-Voices of Hypopara survey participant

ER and/or Urgent Care Staff May Not Know About Hypopara Signs and Symptoms

- **56%** of participants who visited the ER and/or urgent care felt the staff did not know how to manage a hypocalcemic event/calcium crash, highlighting the need for broader education about hypopara, particularly in the ER or urgent care setting
- **73%** of participants who visited the ER and/or urgent care in the past year said they had an average to terrible view of the care they received
- As a result of their experiences, **nearly 50%** said they would be less likely to return in the future for treatment of the signs and symptoms of hypopara

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The fatigue, brain fog and muscle complications have completely changed who I am and how I can function.

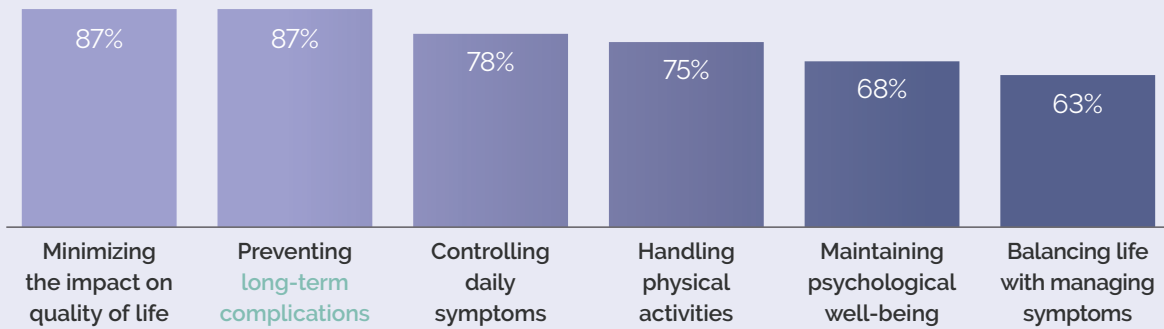
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Top 6 Challenges Patients with Hypopara Face



- Long-term complications are an important concern
 - For participants concerned with preventing long-term complications, 29% were extremely concerned with the long-term effects of hypocalcemia given its impact on the heart, kidney and other organs
 - Patients with hypopara have a 4- to 8-fold increase in risk of kidney disease

Voices of Hypopara – Greatest Challenges



...maintaining adequate calcium levels on a daily basis and concern over the long-term risks of taking a large amount of calcium supplements

...the stigma that comes with looking healthy but not always being healthy

...coming to terms with having a permanent disability

...low level of knowledge in the medical profession about hypoparathyroidism and how to manage it

...feeling vulnerable because of dependence upon medication for survival and not having many viable alternatives for therapy

...finding a doctor who understands and listens

...not knowing how I'm going to feel from day to day

...grieving the loss of my intellectual and academic strengths and future

-Voices of Hypopara survey participants



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