

New Survey on World Hypoparathyroidism Day Highlights Need for Awareness of this Rare Endocrine Disorder and Patient Challenges to Receive Adequate Care

- Disease education needed, especially in emergency or urgent care setting -
- Voices of Hypopara survey describes complex patient journey, and need for a strong patient and physician partnership -

LEMOORE, CALIFORNIA, June 1, 2020 – In support of World Hypoparathyroidism Awareness Day, the HypoPARathyroidism Association (HPA) today released findings of its recent survey highlighting the experiences of patients living with hypoparathyroidism (hypopara or HP) in the United States (U.S.). The Voices of Hypopara survey revealed that the majority of patients with this rare and complex endocrine disorder still struggle to receive adequate medical care, including in the emergency room (ER) or urgent care setting.

Hypoparathyroidism causes low levels of calcium in the blood due to insufficient amounts of parathyroid hormone. Hypoparathyroidism is mostly caused by thyroid (neck) surgery, but also results from idiopathic, genetic or autoimmune issues. It can lead to a wide range of physical and emotional symptoms, as well as severe long-term complications related to calcification in the kidney, brain, blood vessels, eye and other soft tissues.

In this survey of 146 people living with hypopara, an overwhelming 69% of participants reported experiencing a ‘calcium crash’ – a potentially life-threatening decrease in calcium levels – at least once in the past year. Of these, 43% reported calcium crashes weekly or monthly, and 4% daily. A calcium crash can cause an inability to speak or breathe, involuntary or painful muscle spasms and even seizures.

Additionally, approximately 42% visited an ER and/or urgent care facility in the last year to address their symptoms; half of these visited two to four times, and another 18% visited the ER and/or urgent care even more often in the past year.

The survey also highlighted the complexity of the hypopara patient journey, including diagnosis. For half of the participants, it took more than five physician visits, and for a quarter of them, more than a year before receiving a diagnosis. In approximately 10% of participants, it took over a decade for their disorder to be diagnosed.

“These striking results show that, while we’ve made great progress, we have more work to do to educate the medical community and public about hypopara, especially in the emergency setting,” said Deb Murphy, President and Vice Chair of the Board of Directors of the HypoPARathyroidism Association. “It was heartening to see that those participants who cited positive ER experiences said they played a key role in educating the staff about hypopara. 1
Patients driving medical education and empowering themselves – I can’t think of anything more

exciting to see. By continuing on this path, I know we'll be able to make a difference. It is an honor to be able to present the results of our survey and give voice to patients with hypopara on World Hypoparathyroidism Awareness Day.”

Results of the survey also provide insight to the experiences of those living with hypopara who seek emergency care:

- 73% of participants who visited the ER and/or urgent care in the past year (n=62) had an average to terrible view of the care they received. As a result, nearly 50% stated they would be less likely to return in the future for treatment of the signs and symptoms of hypopara.
- 56% felt the ER staff did not know how to manage a hypocalcemic event/calcium crash, highlighting the need for broader education about the disorder, particularly in the emergency setting.

In some cases, the calcium crash episodes are so serious they may require intravenous (IV) infusions of calcium in an ER or urgent care facility:

- 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.

“As an endocrinologist, managing hypoparathyroidism is one of the more complicated and challenging conditions. Greater awareness is needed across the healthcare community,” said Mishaela Rubin, M.D., a member of HypoPARathyroidism Association’s Board of Medical Advisors. “It is also critical that patients and physicians work together to anticipate and manage all the different aspects of this disease to minimize its day-to-day impact, and to reduce its burden to the healthcare system.”

Additional key findings include:

- Nearly all patients received standard-of-care treatment (calcium and active vitamin D), and the majority (69%) felt their treatment was moderately to extremely burdensome.
- Almost all patients changed their medication regimens at some point, with 61% changing more than five times since being diagnosed. The frequency of medication changes reflects patients’ struggles to manage hypocalcemic events/calcium crashes with available therapies.
- The most frequently cited challenges related to minimizing the impact of hypopara on their quality of life (87%), preventing long-term complications (87%) and controlling daily symptoms (78%).
 - For participants who were concerned about 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.
- A majority of participants also indicated that their hypopara has negatively impacted 2 their level of employment.

- When asked about the impact of COVID-19 on their ability to manage their disorder, the majority (52%) reported no or minimal impact. However, 14% reported a significant impact. Reasons for those who reported an impact were not being able to see a physician or get routine labs, and an overall increase in anxiety or fear.

Of the 146 who participated in the survey, 89% were women and the average age was 51 years. The majority of participants (80%) were diagnosed after surgery; 11% were diagnosed due to idiopathic/unknown reasons; and 9% were diagnosed due to autoimmune or genetic causes.

About the Voices of Hypopara Survey

The Voices of Hypopara research survey evaluated the experiences of 146 U.S. patients living with hypoparathyroidism (hypopara or HP), and was supported by Ascendis Pharma. The survey was fully anonymous and conducted online during April and May 2020.

About 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. The disorder affects approximately 200,000 patients in the United States (U.S.), Europe, Japan and South Korea, and at least 80,000 in the U.S. alone. The majority develop the condition following damage or accidental removal of the parathyroid glands during thyroid surgery. This condition can also be inherited or associated with other disorders.

Patients with hypopara 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 major complications, such as calcium deposits occurring within the brain, eye, blood vessels and kidneys, which can lead to impaired renal function.

Until recently, hypopara remained among the few hormonal insufficiency states not treated by replacement of the missing hormone. Standard of care with active vitamin D analogs and calcium supplementation do not fully control this disorder, which contributes to a 4-fold to 8-fold greater risk of renal disease as compared to healthy individuals.

About the HypoPARAthyroidism Association

The HypoPARAthyroidism Association is a nonprofit organization dedicated to improving the lives of people impacted by hypoparathyroidism and their caregivers through education, support, research and advocacy. Founded in 1994 by James Sanders, the Association has grown to include approximately 4,000 members in 70 countries and hosts an annual international conference to bring the medical and patient communities together for mutual exchange of how to treat and live with this rare disease. For more information, please visit www.hypopara.org.

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