

Useful Resources

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If you have any questions or comments or would like to get involved, we would love to hear from you.

HypoPARathyroidism Association



Together Growing Stronger ~ Together Making A Difference

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What is hypoparathyroidism and pseudohypoparathyroidism?

Hypoparathyroidism (Hypopara or HPTH) is a rare medical condition which is characterized by hypocalcemia (low blood calcium), hyperphosphatemia (high phosphate levels), and low or inappropriately normal levels of parathyroid hormone (PTH).

Pseudohypoparathyroidism (PHP) is characterized by hypocalcemia and hyperphosphatemia. Unlike hypoparathyroidism, however, it is not a defect in the PTH production, but rather, peripheral resistance to the PTH hormone.¹

What is the HypoPARAthyroidism Association?

The HypoPARAthyroidism Association, the first patient organization in the world dedicated to hypoparathyroidism, was founded by James Sanders in 1994 after meeting another person who had hypoparathyroidism besides his family. Building on the feeling of no longer feeling alone, he decided that others should have a place to go for reliable information about hypoparathyroidism, educate the public and medical communities, and build a community where people would no longer feel alone while dealing with this disorder. Today the HypoPARAthyroidism Association has over 5,000 members in 70 countries and is advised by top medical experts in the area of hypoparathyroidism. The Association is supported by grants from various foundations, corporations and private donations.

Why are we needed?

It is challenging to maintain serum calcium levels and most physicians know little about this rare medical disorder or the current treatment methods (some of which are not ideal) for managing the symptoms. Many patients are not able to get properly diagnosed and as a result are left unmanaged or mismanaged. They are left to struggle and feel alone and isolated. We try to empower those with hypoparathyroidism through education and support.

Through research in the last 20 years, much has been learned about hypoparathyroidism. A hormone replacement therapy has been recently approved, however, much still needs to be learned. It is our hope that we can make a difference by helping the medical community gain a better understanding of this rare disorder and as a result improved the quality of life for those dealing with hypoparathyroidism.

What do we do?

We focus on supporting and educating those with hypoparathyroidism, raising awareness and providing educational opportunities to the medical community. We also raise funds for future research into hypoparathyroidism.

Patient registry – We were the first hypoparathyroid organization to maintain patient registry. Because of this registry we have been instrumental in providing opportunities to members for research trials.

Research – We have always supported medical research through member participation in clinical trials, patient studies and surveys, and so forth. Much of the progress in hypoparathyroidism is possible because of the wide spread support of our members.

Raising Awareness – We have a comprehensive website and make use of social media. We involve local media, speak out in the press, have a growing collection of patient stories as well as short videos explaining aspects of hypoparathyroidism to the general public on YouTube.

World Hypoparathyroidism Awareness Day (WHAD) – Together with our sister Associations we spearheaded the creation of June 1st being dedicated a hypoparathyroidism awareness day worldwide.

Quarterly Newsletter – Since our foundation we have printed a quarterly newsletter with articles, “Living with HypoPARA” stories, and other useful information regarding hypoparathyroidism. It is currently available by subscription, which also helps to support our website and other programs.

Patient Education – We maintain a website with a wide variety of resources such as our *Quick Guide to Understanding Hypoparathyroidism* and online classes by leading experts. We also provide an annual patient conference, held in June each year, inviting researchers and leading experts to speak.

We are currently working with medical experts to develop educational programs for medical community well as the hypoparathyroidism community.

Peer Support for Hypopara Patients - We maintain a toll free 24/7 hotline (1-866-213-0394), where we take calls from around the world. We also maintain a private online forum through our website and also social media support groups. Our conferences are also a time for patients to meet face to face and forming lasting friendships and support systems. If needed, we help in finding a physician in a member's locale.

Physician Support - We facilitate contact between our members' physicians and members of our medical advisory board as needed. We also maintain a web page for physicians.

Fundraising – We have created the Billy Sanders' Memorial Research Fund that will help provide grants to those conducting research into hypoparathyroidism. We hold an Annual Auction in conjunction with our conference to help these raise funds. We encourage everyone to donate or raise funds for this endeavor.

Networking – We are a member of the National Organization for Rare Disorders (NORD), RARE Disease Day, and when possible attend professional medical conferences such as the Endocrine Society Conference. We have spoken at the Thyroid Cancer Survivors Association (ThyCa) annual conference for several years. We also work with other organizations on a varying basis.