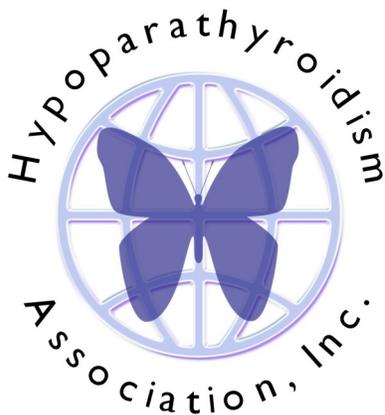


# The HypoPARA-Post

Celebrating 20 years of Making a Difference!



## 8th International Conference on Hypoparathyroidism Sacramento, California 2014

Inside this Issue: Conference Memories - Introducing our New Volunteer Advisory Committee - Living with Hypopara: Vivian's Story - The Gift of Breath - NORD Patient Meetings - Conference Musings: My Journey to Sacramento - Review of Paper: "Surgeons and Patients Disagree on the Potential Consequences from Hypoparathyroidism"

# THE HypoPARA-Post

Volume 20, Issue 3, 2014

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Our suggestions and comments are based on our collective experience, both personal and collective. While the suggestions and comments we have offered have been successful for many individuals, we do not mean to imply they will be successful for every individual and under every circumstance. Proper medical treatment is intended to be a personal matter between the patient and his/her own physician. Any suggestions or comments offered are intended to help the patients and their physician(s) determine the best course of action.

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## Jim's Corner

by Jim Sanders, President

The 8th International Conference on Hypoparathyroidism, held in Sacramento, California, this past June, is now history. From all reports, it was a huge success, and everyone went home empowered to take a more active participation in their medical care. The speakers who spoke during the conference succeeded in educating everyone who was able to be there.

It was the first time we had held our annual conference outside of the Washington D.C. area. We could not have pulled it off without the help and assistance of many people, too numerous to mention. Thank you! Thank you! Thank you! We want to acknowledge and offer our thanks to all the speakers for their hard work and excellent presentations on your behalf. We cannot say enough about Dr. Bart Clarke, Dr. Dolores Shoback and Dr. Aliya Kahn who each received a special award from the Hypo-PARathyroidism Association for their tireless work and support of the Association and for each of you.

Dr. Shoback and her colleagues were instrumental in lining up physicians from San Francisco and Northern California who were able to attend and to speak at the conference. It does not seem adequate to say "Thank you", but sometimes that is all that is necessary.

We want to thank everyone who attended, and look forward to seeing you next year!

Speaking of which, we will host the 9th International Conference on Hypoparathyroidism in Minneapolis, Minnesota on June 4-6, 2015. We have already lined up several speakers, and the ninth conference stands to be even bigger than the eighth conference just concluded.

Hypoparathyroidism is coming of age!

So much is going on in the world of hypoparathyroidism that we need your help. We have created a new Volunteer Advisory Committee. More information about this committee and how to volunteer appears on page 12 of this newsletter.

Dr. Dan Ruan, one of our Medical Advisers, and his associates were finally able to get their paper published. Our members, you, have been talking for years about how the consent forms signed by patients before surgery are inadequate and patients need, and deserve, more information before they consent. Surgeons just do not understand what hypoparathyroidism means and the consequences when things do not go as expected. Perhaps they will now. Dr. Kim reviewed that article for this newsletter.

The Journal of Endocrine Practices Journal published the PARADOX Study in May 2014, describing details of quality of life and the burden of impact of hypoparathyroidism. You made this paper possible with your interviews and by completing the surveys used by the authors.

The American Association of Clinical Endocrinologists, AACE, has generously allowed us to post a copy of the [PARADOX article](#) on our website and is allowing our members to print one copy for their personal use without charge. Please honor their request of one copy per member. Dr. Kim will review this landmark study in our next newsletter.

The FDA asked the HypoPARA-tyroidism Association to testify at their public hearing for Natpara. We are honored to be able to speak for the many hypopara patients. It is gratifying to see all our hard work for the past twenty years possibly come to fruition. All that remains is to wait for their decision on October 24th. I wish I had a crystal ball!

The conference was a fabulous learning experience and taught me so much more than I could hope.

- Conference Attendee, June 2014

# A Review of the Paper: “Surgeons and Patients Disagree on the Potential Consequences From Hypoparathyroidism” by Cho NL, Moalem J, Chen L, Lubitz CC, Moore FD, Ruan DT.

By Kim, MD

[Endocr Pract.](#) 2014 May 1;20(5):427-46. doi: 10.4158/EP13321.OR.

## Abstract

**Objective:** To test the hypothesis that surgeons and their patients underestimate the potential negative impact that permanent hypoparathyroidism has on quality of life (QOL). **Methods:** We used a modified SF-36 assessment tool to compare the perceptions of patients with permanent hypoparathyroidism to the perceptions of control subjects who were given a standardized preoperative statement about the complications of hypoparathyroidism. We also elicited the perceptions of endocrine surgeons regarding the QOL impacts of hypoparathyroidism using a subset of questions from the modified SF-36. **Results:** A total of 340 postsurgical patients with permanent hypoparathyroidism, 200 controls, and 102 surgeons participated in the study. Both surgeons and controls underestimated the negative impact of hypoparathyroidism on QOL when compared to patients living with permanent hypoparathyroidism. Forty-seven percent of hypoparathyroid patients believed that their health was "much worse" than before surgery, compared with 16% of surgeons ( $P<.001$ ) and 7% of controls ( $P<.001$ ). Postoperative hypoparathyroid patients also reported far more negative effects on QOL, from interference with social activities, paresthesias, muscle cramping, and medications than were anticipated by surgeons or controls ( $P<.05$  for all comparisons). In each of the 8 dimensions of QOL, including physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health, hypoparathyroid patients re-

ported a significantly lower mean score compared to the control group ( $P<.001$  for all comparisons). **Conclusion:** The impact of postoperative hypoparathyroidism on patient QOL is consistently and significantly underestimated by surgeons and subjects receiving surgical consultation.

## Summary and Review

Recently, a very important article was published in *Endocrine Practice* by Drs. Cho and Ruan and colleagues (from the Department of Surgery at Brigham and Women's Hospital and Massachusetts General Hospital in Boston, MA; and University of Rochester Medical Center in Rochester, NY); the abstract is above. This is particularly important for future prevention and care of post-surgical hypoparathyroidism (HPTH), the largest and fastest growing group of HPTH patients. All too often, including at the recent Hypoparathyroidism Association conference in June 2014 in Sacramento, patients with post-surgical HPTH and/or family members express how upset they are that their surgeon(s) did not inform them of how life-changing and detrimental to the quality of life HPTH could be, as a potential complication following a thyroidectomy or other neck surgery. Much of this occurs because surgeons do not understand the impact that HPTH has on patients' lives, believing it to be a condition readily treated simply with some extra calcium and vitamin D supplements. This study by Cho et al showed there was a statistically significant difference in how surgeons view the consequences of HPTH, compared to

patients living with permanent HPTH. This awareness is an important first step in educating the entire surgical physician community at large regarding the importance of providing accurate and realistic informed consent, as well as increasing the efforts to prevent this life-altering complication. The fact that the study authors included surgeons themselves is all the more important. It shows the first hope that this finding will be disseminated to the rest of the surgical community and indicates that surgeons and their colleagues are beginning to acknowledge that the informed consent procedures for thyroidectomies and neck surgeries need to be improved. I will summarize the study and at the end provide my own commentary from the viewpoint of both a physician and a HPTH patient.

## INTRODUCTION & OBJECTIVES

Permanent postoperative HPTH is defined as having too little parathyroid hormone (PTH) production to maintain normal calcium levels for six or more months after surgery, and is the most common complication following total thyroidectomy surgery. Patients with this condition need to take calcium and vitamin D supplements multiple times a day to avoid neuromuscular symptoms such as numbness and tingling around the mouth and extremities, muscle cramping, and fatigue. Before thyroid or neck surgery, patients should have a satisfactory level of understanding regarding treatment options and potential risks of surgery. An accurate understanding of the impact that potential surgical complications may have on future quality of life

(QOL) is essential for each patient prior to consenting to proceed with surgery.

No previous studies have compared the expectations of patients who have gone through the informed consent procedure to those of patients who actually live with the permanent postoperative HPTH complication, in contrast to the perceptions of the surgeons who are performing these surgeries. The objective of this study was to compare the perceptions of QOL burdens from HPTH between (1) surgeons, (2) volunteer preoperative patients (“controls”) who were given information regarding complications resulting from thyroid surgery, and (3) postoperative patients who actually lived with permanent hypoparathyroidism.

## METHODS

There were a total of 642 participants, broken down into three groups: (1) 102 “experienced endocrine surgeons,” (2) 200 preoperative controls, and (3) 340 post-operative patients with permanent HPTH. The survey instrument used to measure QOL was the Short Form (SF)-36 (more information on this can be found here: <http://www.sf-36.org/tools/sf36.shtml>). For the preoperative controls, the language on the SF-36 form was modified to ask, “How would you expect to feel (or your health to be) after neck surgery?” For the surgeons, in order to improve response rates, the SF-36 was shortened to just six questions that were specific to HPTH. Specifically, the language of the survey asked the surgeons to think about patients for whom neck surgery caused hypoparathyroidism, with questions asking them to rate these patients’ general health now; their health now as compared to their health prior to surgery; how much the physical or emotional problems of these patients interfered with their

normal social activities; and how much they expected these patients to experience symptoms of pins and needles sensation, muscle cramping, and medication interfering with daily life after their neck surgery. The preoperative controls and postoperative patients were given the entire modified SF-36 questionnaire (with 54 questions; 36 regarding views on general health, 13 related to medical history and HPTH symptoms, and five for demographic information), which was completed by the participants on their own. All participants were at least 18 years old. The surveys were administered in English only, and hosted on the website Survey Monkey (<http://www.surveymonkey.com>).

The preoperative controls were given a standardized preoperative statement describing the risks and consequences of permanent HPTH; this statement was established from a panel of six “expert endocrine surgeons.” Specifically, the survey stated, “We understand that, in reality, you are not a patient undergoing this operation. However, we ask you to imagine that you are a patient who is considering surgery and has just discussed the potential risk of hypoparathyroidism with their surgeon. In this hypothetical scenario, the surgeon tells you that: **‘In this operation, there is a risk of accidentally injuring the parathyroids, which are glands in the neck that are about the size of a grain of rice, that regulate the calcium levels in your body. If these glands are permanently damaged because of manipulation or removal, you could be left with low calcium levels for the rest of your life, a condition called hypoparathyroidism. The risk of this happening is approximately 1-4%. If it occurs, you will need to take large doses of calcium up to four times a day plus vitamin D supplementation to avoid symptoms of low calcium levels.**”

**These symptoms typically include numbness around the mouth, a sensation of pins and needles in your hands or feet, and sometimes muscle cramping.**’ Based on your reaction to this statement, pretend that you are about to undergo surgery. The following questions will ask how you would expect to feel if you suffered from hypoparathyroidism.” The controls were recruited to take the survey by advertisement. The permanent HPTH patients were recruited online through the Hypoparathyroidism Associations, located in the USA and the United Kingdom. Surgeons were recruited through e-mail addresses from American and International Associations of Endocrine Surgeons.

The SF-36 survey tool evaluates eight dimensions of QOL, with a total of 36 questions. The number of questions contributing to each domain varies from two to ten, and the scores range from 0 (poorest health status) to 100 (best health status). Statistical analyses were performed to compare mean scores of the eight dimensions of QOL between postoperative patients and controls, as well as to compare selective questions on the modified SF-36 between the postoperative patients, surgeons, and controls.

## RESULTS

A total of 102 surgeons out of 518 of the e-mailed surgeons responded to the survey (estimated response rate of 21%). A total of 200 preoperative controls were surveyed. A total of 400 postoperative HPTH patients responded to the online request for participants. Of these, 60 patients were excluded because they were not on calcitriol or did not suffer from postoperative HPTH. The majority of both preoperative controls and postoperative HPTH patients were female, with an even greater female predominance in the postoperative

group (90% vs. 67%). Ages were similar in both preoperative controls and postoperative HPTH groups (median 46 vs. 50 years). There were more control group participants earning >\$90,000 per year in income (30.3%) than in the patient group (15.0%); it is unclear whether this relates to potentially more patients being on disability and/or unable to earn a higher income due to the HPTH, as this information was not included in the study. Both groups were mostly Caucasian (79.0 and 93.5% respectively), with more Asians (12.4%) in the controls than the patient group (1%).

*Both surgeons and controls underestimated the negative impacts of HPTH on QOL compared to postoperative patients who lived with the disease.* While 47% of the postoperative HPTH patients believed their health status was “much worse” after their surgery, only 16% of surgeons and 7% of controls expressed the same opinion. Likewise, 53% of the postoperative patients experienced significant numbness/tingling symptoms, while only 26% of surgeons and 12% of controls thought this would occur. Similarly, 51% of the postoperative patients reported significant muscle cramping, while only 16% of surgeons and 11% of controls believed this would occur. This trend occurred across all dimensions that were compared among the three groups, with postoperative patients reporting far more negative effects than anticipated by either the surgeons or the controls, and with more surgeons believing there would be significant negative effects than the controls.

*Patients with HPTH reported significantly lower QOL scores than controls.* In each of the eight dimensions of QOL on the SF-36, HPTH patients reported significantly lower scores than the control group anticipated; the

largest difference was in the energy/fatigue dimension (average rating of 30 in postoperative patients vs. average predicted rating of 64 in controls). Striking differences were also seen in QOL limitations due to physical health, emotional symptoms, and general health concerns. All the dimensions, besides physical functioning and pain, had more than a 20 point difference between the two patient groups. All these dimensions were not compared between the surgeon group and the patient groups because the surgeons were only given the abbreviated six-question version of the survey.

## DISCUSSION

Successful informed consent procedures prior to any surgery rely on effective communication between the physician and the patient of the risks of complications vs. the benefits of the surgery. This is the first study to compare preoperative perceptions of a surgical complication to the experiences of actual postoperative patients who live with the consequences of the complication. The results showed that control group patients who had not yet undergone the surgery but were given “informed consent” information regarding the risks of HPTH consistently underestimated the negative effects of HPTH. They underestimated this even more than surgeons, who also significantly underestimated it compared to postoperative HPTH patients. This study suggests that the current informed consent procedures are suboptimal, as patients often do not properly understand the risks of surgery when they are considering all their treatment options. Patients may choose different treatment options, especially if their thyroid disease is not cancer, if they understood the actual negative impact on QOL that the HPTH postoperative complication could have for the rest of their lifetime.

There were some limitations to the study, including “selection bias” due to non-responders in the populations of surgeons and patients. Hence, those who selectively chose to respond to the sur-

vey may have been more likely to answer the questions a certain way (for example, the HPTH patients who responded may have been more likely to participate in the survey because they were suffering with more symptoms and were seeking patient support through the HPTH Association). The controls were recruited from the general population rather than actual preoperative patients contemplating thyroid surgery, so as to reduce the bias that most actual patients would have by having already decided to proceed with that particular surgery. This also minimized the bias that could occur from actual preoperative patients facing a new cancer diagnosis or having physician(s) recommending surgery having some influence on their perceptions when answering the survey.

## COMMENTARY

This study, in my opinion, represents one of the most important first steps in preventing future postoperative HPTH complications. If surgeons don't agree to recognize that HPTH is a serious complication, they will likely not take as much care to prevent the complication. From my own experience as a patient, much of the preoperative informed consent was centered on the risks of recurrent laryngeal nerve injury, which could potentially leave one hoarse or with voice problems for life. This was what I was most terrified of, because the surgeon actually acknowledged the serious nature of the complication – but also explained the resources available at my institution, such as voice therapy through an Ear, Nose and Throat (ENT) physician, to address it if it occurred. The HPTH complication was “blown off,” just mentioned briefly as a real possibility, but it was implied as being “no big deal since it is easily treated by taking extra calcium and vitamin D, and lots of postmenopausal women take those supplements anyway.” In my opinion, the statement established by the

six expert endocrine surgeons was actually quite representative of what my surgeon explained to me preoperatively about HPTH, and perhaps even more than what was discussed with me -- which underscores just how much improvement still needs to be made in the informed consent process since even this statement already did not convey the impact of HPTH on QOL well. The statement that was provided in this survey for the controls actually mentioned “large doses of calcium ... to avoid symptoms of low calcium levels,” but gave just three symptoms as being typical (with muscle cramping mentioned as occurring only “sometimes”). In light of the PARADOX study just recently published (it is available on the [ww.hypopara.org](http://www.hypopara.org)) and the previous study by Bohrer and colleagues that I summarized in the last newsletter, it would be appropriate for surgeons to acknowledge more symptoms as being typical of low calcium levels, such as fatigue, muscle weakness and pain, difficulty exercising, cognitive and emotional difficulties, among

others. Surgeons should also explain the possibilities of temporary disruption (short-term) vs. permanent (long-term) parathyroid damage, including the likelihood of each and the possibility of requiring IV calcium, with additional hospital time, if the calcium levels drop dangerously low.

With this study, for the first time, surgeons themselves are acknowledging that they underestimate the negative consequences on QOL that the HPTH complication has for postoperative thyroidectomy (or other neck surgery) patients. The conclusion of this study explicitly “calls into question the adequacy of existing informed consent procedures and suggests that there is a need to improve preoperative counseling techniques.” If the informed consent techniques are improved, at least when the HPTH complication occurs, the patient(s) will not be blindsided and/or angry because the reality of living with the condition is far more detrimental on QOL than anything they were led to believe preoperatively. Hopefully we at the HPTH Association can help disseminate this study’s find-

ings to the Endocrine Surgeons and Endocrinologists at large. Once it is “accepted medical knowledge” amongst physicians that HPTH is associated with significant negative QOL domains, then it is likely that Endocrine Surgeons will start developing innovative strategies to reduce this complication, and Endocrinologists will start to acknowledge and treat the permanent postoperative HPTH patients’ symptoms and QOL from a more holistic perspective. Even with this knowledge, educating and changing surgeons’ informed consent procedures will likely still be difficult, as currently management of thyroid cancer, parathyroid adenomas, and head and neck cancer is usually of a somewhat urgent nature. Surgery should always be done by the best available (endocrine) surgeon. However, bearing this in mind, the consequences of surgery still need to be acknowledged and not minimized, and efforts need to be devoted to reducing the risk of postsurgical HPTH, as well as discovering a way to cure hypoparathyroidism someday.

June 1st was the 4th World Hypoparathyroidism Awareness Day and NPS Pharma showed their support by wearing our Logo Shirt!



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## Considerations for Your Hypoparathyroidism Treatment

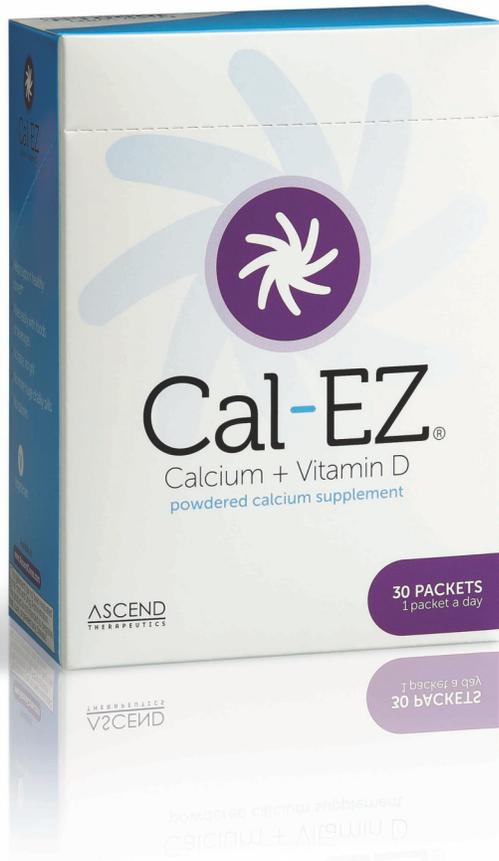
When managing your hypoparathyroidism every day, you have options when choosing your calcium supplement. The type, amount, and tolerability of your calcium supplement are important considerations.

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# Conference Musings: My Journey to Sacramento

By Lisa Simmon

When James Sanders asked me to write about my journey to the Conference on Hypoparathyroidism, it got me thinking.... 2 years ago, I had never heard of a parathyroid. I knew what my thyroid was... but a paraWHAT? How can four little glands the size of a grain of rice cause so much havoc???

Like 80% of HPTH patients, I have hypoparathyroidism due to surgery. However, mine wasn't a mistake or error made by my doctor. I have Multiple Endocrine Neoplasia 1 (M.E.N.1), which is a rare disorder that causes tumors on my endocrine glands. And like most M.E.N.1 patients, I had hypoparathyroidism. So 17 months ago I happily went in to remove this adenoma on my parathyroid gland that was causing chaos throughout my body and I was warned that it was possible I could have more than one gland affected.

The story about my 20 minute surgery turning into 4 hours and awakening to find out that they had done a complete parathyroidectomy with an (unsuccessful) auto transplant and what followed isn't important. We all have 'our stories' that brought us here and the point is, if you are reading this, either you or a loved one is affected by hypoparathyroidism (HPTH). Either through surgery or genetics or immune related.... The cause isn't important, we are here and we can't change that, but luckily we found each other. And hopefully together we can bring awareness and we can change the way the medical community treats HPTH patients and the warnings they give to potential surgical patients. We are real, and we deserve more than the 5 minutes they spend 'reading' about us in medical school!

Arriving at the conference was almost surreal. For the first time in over a year, I was with people that understood what my body had been going through. I didn't need to explain or make excuses or put on a happy face if I wasn't feeling it. I was alone with about 200 strangers, but

I felt like I was at home. And that first day in Sacramento, I listened to a doctor tell a story about a parathyroid transplant patient who was young and had been full of life before she got hypoparathyroidism but when he first met her, she had no quality of life and no hope, she was walking around with an IV attached to her arm.... It made me cry. I was so overwhelmed by emotions, not only because I could relate to her story and her rapid decline in the quality of her life, but also because she was sitting next to me, and this 'magic' doctor had found a way to bring life back into this woman. She looked strong and healthy and she gave me hope for the first time in over a year! It didn't even matter what he was saying or the fact that she still has her struggles, just knowing that there are doctors in this world who MIGHT be able to help, was what I needed. And if you didn't make it to the conference, I am sorry. I cannot tell you how important it was for my knowledge on treating this chronic illness and also for my outlook on life. (Thank you to everyone at the HypoPARAthyroidism Association for bringing us together.)

I guess if I want people to understand how HPTH has affected my life, I need to explain who I was before. I'm a single mother of a 10 year old son. He and I are explorers at heart. We've traveled throughout Canada, Europe and the Middle East, we've slept in hotels made out of ice and even spent Easter at the White House for the egg roll. I've raised my son to go with the flow and not look back. When there was something we wanted to do, we did it. Just before my surgery, my son and I were planning our big adventure to Antarctica, we would find a place on this crowded earth no man had ever stood and we'd be the first... I had no idea how the surgery would change my life and more importantly, how LITTLE the medical community actually knows about HPTH and electrolyte imbalances. I was told I might need to take some Calcium supplements, but I was never warned what life

with HPTH could be like. Since my surgery I spend my days trying to find the energy to pick up my son from school and still be able to make dinner for him. There is a fatigue that never goes away. I have pain in my bones, muscles and joints and some days, getting out of bed isn't an option. I took my son on a mini-vacation to a water park this summer and I spent 3 weeks trying to recover and stabilize my electrolytes. (8 of those days were spent in a hospital). Thanks to the tetany seizures that move into my chest, I am a frequent overnight guest at my local hospital where all the interns come to 'tap my cheek' once they hear I'm in the building! There is brain fog and migraines and so many other issues it's overwhelming.... I went from taking care of my son and my mother to being the one that needs to be taken care of. I went from exploring countries, to not being able to do my own grocery shopping! I know what it means to have your quality of life stripped from you.

Being at the conference and listening to the presentations by Drs. Clarke and Khan and knowing that there are doctors who actually understand what some of us go through has put a fight in my soul. I won't settle for a doctor who wants to wait and see. I will fight my insurance company until they realize that people with rare illnesses need specialists. Normal endocrinologists don't have working knowledge of what we go through. I know that there are treatments and one day I will find the right one. I might not be a candidate for the PTH 1-84 clinical trials, but I have hope that the FDA will approve it. I might not be a candidate for a transplant, but knowing that a doctor is willing to explore new options and doctors are doing stem cell research lets me believe that one day the right treatment will come and The conference was a fabulous learning experience and taught me so much more than I could hope. I can be me once again.

# CONFERENCE MEMORIES

To say that the 8<sup>th</sup> International Conference on Hypoparathyroidism was a success would be an understatement. Each conference we have held since our first one in 2006 has been more successful than the previous one. Not only have they become an important way of educating our patients about hypoparathyroidism; our speakers have come to see them as essential to them and their work.

Something good comes from having so many patients and caregivers in the same room at the same time as the medical experts who have devoted their professional careers to hypoparathyroidism. The speakers, as usual, presented a discussion of various aspects of hypoparathyroidism.

Lifetime friendships were born, and several friendships made in previous conferences were renewed. I could feel the excitement building in our members as they counted down the days until the conference, and you could feel the intense excitement in the air once it began.

One of the highlights was when we presented achievement awards to three of our medical advisers: Dr. Dolores Shoback, Dr. Bart Clarke, and Dr. Aliya Kahn, three of our strongest supporters and cheerleaders. The simple words on the plaques cannot thank them enough for all they do for each of you and for hypoparathyroid patients everywhere. We will forever remember the fact they unselfishly gave of their time, talents and their education to help each of us.

Some of the attendees were so excited their calcium got ahead of them and they crashed. One did not need to ask, “Is there a doctor in the house,” because someone always came to the rescue.

I think most will agree it was one of the best conferences we have had. It was educational and a lot of fun at the same time as you can see by the pictures that follow. We hope to see you all at next year’s conference in Minneapolis on June 4-6, 2015. Watch the site for more information.

A special thank you to our official photographer, Larry Campbell - the link to all the conference pictures is located in the conference materials section on the website.





# Advocate for Yourself and Get Involved in the HypoPARAthyroidism Association

By Ann Purchase

My story is probably very similar to many of you. It begins a bit dismally, but ends on a very positive note thanks to the HypoPARAthyroidism (HypoPARA) Association!

I needed a thyroid goiter removed after a third biopsy indicated there were changing cells *indeterminate* in origin. Since I had breast cancer, a few years ago, I was really scared that the cancer had returned, and that it was now in my thyroid. I was paralyzed with fear and opted to have the entire thyroid removed rather than just the half with the irregular cells. I had been told that if it were cancer, I'd have to have another surgery in a week and a half to remove the other side. That option sounded dreadful, so I said, just take the entire thyroid. During the surgery, the doctor determined that I had an enlarged parathyroid gland, so he took that as well. He assured me in the recovery room that by removing the parathyroid gland my osteoporosis would improve, so I said, "Oh that's great."

Fortunately, the thyroid cells were not cancerous. I was in the hospital overnight and went home feeling fine. I was put on 3,000mg of calcium/day, but I assumed that must just be precautionary. After one day I had numbness and tingling and twitching everywhere, and it just wouldn't quit, so I called the surgeon and was advised to take more calcium. I developed calf pain and was practically bed ridden the day after skiing. Long story short – for 6 weeks I took probably 4-5000mg of calcium with little relief of the symptoms. I couldn't even *think* clearly! Finally, at the 6 week post surgical appointment, the doctor said I wasn't

absorbing calcium and I was started on Rocaltrol (calcitriol) 0.5mcg twice a day, with the 3,000mg of calcium. I felt better within 24 hours. The brain fog lifted almost immediately with the addition of the Rocaltrol. At my next appointment I asked what my PTH was, and was told it was "4", but I was also told – again - "don't worry, it's probably just a transient condition." Two weeks after starting the Rocaltrol, I ended up in the hospital when I passed out from dehydration after continuous vomiting, lack of appetite, headache and dizziness (classic signs of hypercalcemia). My calcium was way too high – close to 14mg/dL. After receiving intravenous fluids in the ED, again I was assured that the parathyroid hormone would probably return and that the level was even a bit higher (had gone from <4 to 4). What? This was a bit higher? At this point I wasn't very trusting of the medical community and was thinking, "Could someone please tell me honestly what is happening?"

After 4 months, I decided it would be necessary to take matters into my own hands, and this is where the HypoPARA Association comes in! I was desperate to feel like myself again. I began searching the internet, and among my many readings, I found the HypoPARA Association, emailed them, and unbelievably I received a response in a just a few hours! That email was like a lifeline to me and I have reached out many times since that first one. I was asked about my symptoms, how I was taking my medication and just generally how I was feeling. I was encouraged to try taking the calcium in 2 hour increments and that helped a lot to

prevent the big calcium fluctuations.

My husband and I travelled to the Hypopara meeting in Baltimore to meet these wonderful people and we learned so much and met so many others in the same situation. I listened to all of the doctors who had authored all of the hypopara research I had been reading about. I was still on very high doses of calcium, but my 2<sup>nd</sup> endocrinologist at least lowered the Rocaltrol to .25mcg once a day. He said I had been taking so much Rocaltrol that my parathyroids would never wake up.

After the conference, I thought that I'd really like to get into a research study with the synthetic parathyroid hormone, and that I'd like to see one of the HypoPARA Association doctors on the advisory board. We had been encouraged at the conference to consult with one of these doctors. After an initial denial, I filed an appeal with my insurance company and was allowed 1 visit with Dr. Mishaela Rubin at Columbia University. She has been consulting with my latest (3<sup>rd</sup>) endocrinologist ever since. She ordered a 24- hour urine which indicated there was a very high level of calcium in my urine and so we began tapering my calcium so that now I take about 1300mg/day (down from 3,000mg). And, as an aside, I tapered the calcium over 5 months because my body couldn't adapt to abrupt calcium changes. Dr. Rubin also recommended taking less vitamin D2 since my blood levels were almost 100ng/ml, so now they are around 50ng/ml. These changes in medication have protected my kidneys, which was our take home message from last year's conference - *protect the kidneys from the high*

levels of calcium! My 24- hour urine calcium has been maintained at 250mg, way down from 450mg, and I haven't had any kidney stones as a result.

At this year's conference in Sacramento, our take away message was to *advocate for yourself*. Many of the doctors spoke about how important it is to work *with* your doctor. I am so lucky now, because I have a wonderful doctor, who, on my first visit, spent an hour and a half with me. She really listened and determined what was best for me. And, since the symptoms of hypopara are experienced so differently from one person to another, listening to us is the key to understanding what we need to do to manage the symptoms. My latest, and hopefully my last, endocrinologist is the 3<sup>rd</sup> one I have had. I fired the other two who weren't advocating for

me! I was recommended to her after my 2<sup>nd</sup> endocrinologist told me my symptoms *might be psychosomatic*! I cried for hours after that remark, wrote to James at the HypoPARA Association, and had given up hope of finding a doctor who could help and work with me.

I am still grateful for the depth of understanding that my endocrinologist displays at every visit. She has one other patient with hypopara who was born with it, and she thanks *me* for what I am teaching her! What a breath of fresh air she has been. She is like the doctors my husband and I have met at both of the conferences, concerned about our well-being and working tirelessly to support us. Keep searching for this type of doctor because your quality of life will improve immensely.

What I learned from Dr. Rubin is that the first year of hypopara is the worst. The

calcium levels fluctuate and they are difficult to manage. Just having that knowledge made me feel better. My second year is almost done and I'm very stable right now, have minimal symptoms, the urine calcium is under 300mg and I haven't had brain fog for at least 4 months. Things are looking up for me. Having support from the HypoPARA Association, being armed with knowledge, having a wonderful doctor, and support from my husband, friends, and the wonderful people I have met at the Association, have all contributed to this positive outlook - finally. I'm not a negative person by nature, but this has been difficult. If you can, go to the Hypoparathyroidism conference because it will change your life for the better! Listen and learn and get involved!

## Introducing Our Brand New Volunteer Advisory Committee

By James Sanders, President

Running a non-profit takes a lot of work and over time we have grown to a point where we need to make some changes. Over time we have had members approach us about helping with some the work of the Association. With everything going on in the world of hypoparathyroidism now, we are now taking these members up on their suggestions and offer to help.

We have created a Volunteer Advisory Committee that will, to start, be made up of six sub-committees. This allows you to volunteer to help where your talents are best suited and/or your interests lie.

Those who wish to volunteer will be asked to help with one time projects and/or ongoing projects (such as our newsletter). Just how much time you want to commit to is up to you, but we need your help.

Enclosed in this issue is an application to volunteer on this Advisory Committee. We hope you will volunteer to help us help you.

The six sub-committees are: Patient/Physician Education, Newsletters, Member Support, Fundraising, Social Media, and Conferences.

If you have questions, please feel free to contact us at [volunteer@hypopara.org](mailto:volunteer@hypopara.org). Please join us!



# Living With Hypoparathyroidism: Vivian’s Story

By Gerry Lingan, Philippines

Twenty-three years ago, my wife underwent a thyroidectomy because of a cancerous nodule. What was supposed to be a relatively innocuous procedure resulted to a new and dreadful disorder with devastating manifestations, which most of you with hypoparathyroidism now understand and are enduring.

Her life since then has morphed literally with twist and turns that could rival a Chinese kung-fu master.

Compounding her woes was the rarity of her condition, which came as a surprise for those who went through the similar procedure. The absence of the comforting thought, “you are not alone in your condition” makes it more excruciating for her. Confronted, her surgeon, in his prime but shirking like an intern, could only mutter calcium, calcium, calcium ... A substance so ubiquitous yet so scarce in her system.

Because a cure was impossible and controlling her symptoms was difficult, there was not a time in my wife's appointment with her Endocrinologist, who seemingly knows many things but couldn't do anything, that medicine and dosages were not altered: different brand of medicines were tried; timing and dosages adjusted and readjusted; the only thing that stays constant is her symptoms and laboratory values which remains at its ebb.

Over the years, we have spent half of our time searching for cure and the other half plotting to “kill” the surgeon who operated on my wife.

The height of our worries came in

1999 when we were expecting our first child. The perinatologist could not assure us of a healthy pregnancy outcome notwithstanding a healthy biophysical profile of the fetus. Their years of training and experience have never led them to a symptomatic thyroid and parathyroid-less gravid with an annoying husband worried to kingdom come. Fortunately, the pregnancy ended with the spontaneous delivery of a healthy baby boy.

Two more pregnancies followed years thereafter with uneventful outcome. However, her symptoms went unabated. The strains of raising our children added to her miserable condition.

Condemned to a life of misery and with no hope in sight, so I began a long and arduous search for the "Holy Grail" of hypoparathyroidism. Once I read about the HypoPARAthyroidism Association and attended the conference in 2012, a glimmer of hope began to flicker on the horizon. At last, my wife can now find solace in the company of people who can relate to her condition.

Last June 2014, Vivian and I attended the Eighth International Conference on Hypoparathyroidism. It was her first. Learning so much from expert doctors regarding her condition, a look at the past and the strides made to find the cure, gaining insights into the future with stem cells, to simple tips of caring for one's self from her peers, and above all, meeting new friends. The experience was overwhelming.

Right after the conference in the quaint and quiet city of Sacramento, I

noticed my wife donning a smile unseen for the past 23 years. The warm glow of satisfaction was apparent. Pluckier in spirit and equipped with new strategies, she was ready to battle the “beast” that haunts her for so long. This time, the odds are in her favor.

The “Holy Grail” of hypoparathyroidism is no longer a pipe dream. The quest may take some time, but not for long. Unlike King Arthur and his knights, the crusaders (paratroopers) will live to see it through.

Finally, to Mr. James Sanders and his wife Carol, who were very accommodating and made it possible for Vivian to attend, and without whose effort and determination, the association and the conferences would never have existed and materialize, I am profoundly and eternally grateful.

It was very informative. I learned a lot as a caregiver about how to help my spouse.

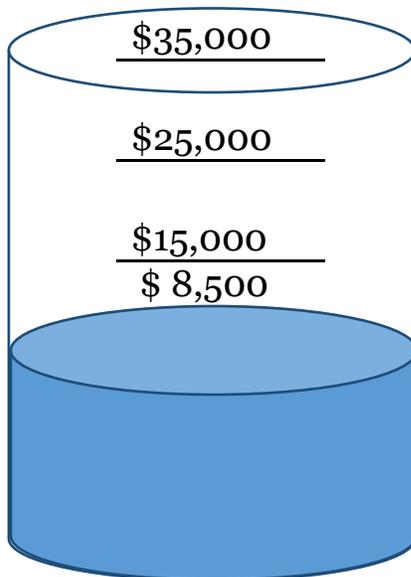
- Conference Attendee, June 2014

## 2nd Annual Silent Auction for Research a Success!

The 2nd Annual Silent Auction for Research held at during the conference raised \$3,000. This brings out Research Fund total to \$8,500, a \$5,000 increase from last year to date.

We want to thank our wonderful members and their families for all the great donations to the Silent Auction. We had some great stuff! Lots of beautiful handmade items along with some local fair. We also had trip to New England included!

Thanks also go to those who bid on the items!



We are now a little over one quarter of the way to our goal of raising \$35,000 for seed money.

Of course, we will gladly accept donations to the research fund at any time; just make sure to tell us it is for the Research Fund.

Have a great idea for raising money for this and other programs? Tell us about it, so we can pass it on to others.

One example, is a member told her friends and family to take the money they would have spent on a card and a gift for her and donate it to the fund instead. This idea raised \$2,000.

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## FDA Requesting Letters on Natpara

By James Sanders, President

As a part of the FDA review of Natpara for the proposed indication of replacement for endogenous parathyroid hormone (1 □ 84) for the long □ term treatment of hypoparathyroidism, the review committee will take into consideration data, information or views in writing from the public. Written submissions may be sent on or **before August 27, 2014** to:

Karen Abraham □ Burrell, PharmD  
 Center for Drug Evaluation and Research  
 Food and Drug Administration  
 10903 New Hampshire Avenue  
 WO31 □ 2417  
 Silver Spring, MD 20993  
 E □ mail: [EMDAC@fda.hhs.gov](mailto:EMDAC@fda.hhs.gov)

It is recommended that the submission be made by e □ mail if possible. The letter can be addressed to the committee chair (Dr. Robert Smith) and members of the Endocrinologic and Metabolic Drugs Advisory Committee, with Karen copied. It will become part of the public record for the meeting.

These letters are a powerful tool in helping the reviewers to better understand the impact to quality of life and the daily challenges of those living with hypoparathyroidism.

These perspectives can be from the patient as well as their caregivers, family members and other loved ones.

# The Gift of Breath

By Christina Barnes

As of July 2014, I am over 8 months past my parathyroid glands transplant. The first 6 months were extremely difficult! High doses of immune suppressants, antibiotics, and anti-virals wreaked havoc on my entire body and while dealing with this I have experienced low calcium on a daily bases. Managing Hypopara is a roller coaster ride of its own but add a parathyroid gland transplant and it is like being on two roller coasters at the same time and traveling in different directions. I have left some dramatic Hypopara symptoms behind me, but I have picked up a few transplant symptoms because of the immune suppressants. Instead of focusing on the new symptoms, let me tell you how things have changed.

Many with HPTH constantly ask what my PTH is now and gauge how well I am doing based on my response. However, let me be clear in that the goal of the transplant was, “Not to create a marathon runner,” as Dr. Benedetti has said quite often. The goal was to improve my quality of life and to stop the weekly tetany. I had tried everything: oral dosing of calcium and calcitriol, HCTZ meds, anti-seizure meds of all kinds, high doses of magnesium and potassium, 24/7 IV infusions of calcium and magnesium and high, frequent doses of Forteo. Nothing seemed to stop the tetany, which most often occurred at normal calcium levels, sometimes even at high calcium levels. The transplant was a last ditch effort to stop the muscular seizures that would close up my airway and debilitate me for days. I call them tetany but after going through the transplant and experiencing true low calcium, I am not quite sure that what I had was true tetany. My “tetany” have puzzled many a doctor, and I have seen some of the best in the country. Dr. Benedetti says that, “There are things about the parathyroid hormone that we just don’t understand,” and what I used to experience is one of those things. Perhaps I had a

PTH related movement disorder that doctors have not diagnosed yet. Here are some ways in which what I feel now is different from what I felt before.



Fall of 2010 while still on Forteo and 24/7 IV infusions of calcium and magnesium.

The tetany that I now experience are like this: I feel the low calcium symptoms in my body before the tetany occurs. For example, if I lift up my arms, they will start tingling; my lips will tingle; my face will twitch slightly, and my toes will cramp and roll into the soles of my feet. Sitting in different positions or placing my arm, just the right (or wrong) way will also cause the tingling and twitching. It can happen in one part of the body and not spread to the rest of my body. I can take high doses of powder or pill form calcium and after an hour or so, the symptoms will subside.

On severe crashes when I haven’t “listened” to my body and taken extra calcium, my legs will go stiff and straight in a severe cramp and at the same time my arms will bend at the elbow and stiffen in that position as my hands form claws. I use one MG Midazolam intramuscular injections to stop the tetany and then take lots of calcium. I am usually wiped out for a day.

Now, the “tetany” that I used to experience were different in these ways.

The only warning I had was a sense that all my energy was dropping out of me. I usually had less than a minute warning and nothing would stop what was coming except a 1MG intramuscular injection of Midazolam - if I got it in time.

My legs did not stiffen straight out, they would flex in and out, as my muscles contracted then released, pulling up to my chest and then down again. My back would also arch back and my arms would pull backwards as well.

My airway would usually become constricted. I always had to fight to breathe, often turning shades of red then blue then grey.



While coming off the IV infusions I experienced 52 episodes of tetany in a two month period. I made this with my Mom’s help and we put it on my bedroom wall so I could stay motivated to keep breathing.

If my foot or hand started cramping it would always take my entire body within minutes, and the seizing would last on average 8 minutes with the longest one lasting almost an hour. Midazolam injections would sometimes stop it after 1-2 minutes but not always. Often it would happen multiple times a day as well.



In 2013 my family and I found Dr. Benedetti and I prepared for the transplant.

Therefore, my transplant has transformed my life because now I no longer wonder if I will be able to breathe day to day. I no longer fear that I will be in the grocery store and a “tetany” will suddenly take my entire body in severe muscular contractions while I writhe on the dirty floor of the supermarket. I can treat my symptoms and feel that I have more control. My PTH at last check was a 13.5 and of course, I want it to keep going up! I want to be a success story like the first woman that Dr. Benedetti treated with the same procedure but I have learned that it is not

about the number it is about the changes to my quality of life. It is about the fact that today, I did not wonder if it might be my last day. I didn’t think about my airway closing and not being able to get that dearly needed breath. Today, I just remembered how I used to be tormented with those things and how lucky I am that I no longer feel that way. Maybe in another year I will be able to report that my brother’s gift of his parathyroid gland has cured me and my PTH is a strong 35. However, for now I am eternally grateful that his gift allowed me to breathe today.



The night before the 2014 Hypopara Conference, from left: My cousin- Darlene Muto, my transplant surgeon- Dr. Enrico Benedetti, HPTH survivor and friend Laura Foust, my transplant coordinator and Doctor of Pharmacy- Maya Campara.



October 22, 2013 My brother and I prepped for the transplant surgery.

# Some Comments About Attending the Conference

By Conference Attendees

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Every year we ask our attendees to evaluate the conference and how we can do better. Each year we also ask what the conference meant to them. Here are some of their responses. We hope it will encourage those who have not attended one of our conferences to consider attending next year in Minneapolis, MN.

As it is every year, the value in the value of conferences comes not from the talks—but from the people attending the conference.

I did not realize how much I did not know!

I feel more confident making supplemental choices now and asking for medical tests.

Even though I have hypoparathyroidism I still need to live life!

Meeting others with the same illness and sharing information is one of the best experiences of this conference.

I had a great time seeing everyone again and making new friends and connections. There is definitely a lot of love among the members of our association. This is what ultimately brings me back year after year.

I really liked the broad range of physicians with specific information on labs and other tests.

It was a fabulous conference. I've been to three and this was the best to date!

It was wonderful. I learned more than I thought I would! Thank you.

This was one of the most important things I have ever gone to in my life.

It was fun, fabulous and VERY informative from a personal point of view, and not just the medical or impersonal sources.

My heart has been tenderized by the pain, the challenges, and the tragedies of the HPTH attendees.

Wonderful!!! Exhausting! Informative! Well put together...thanks to all of you at HypoPara!!!

It was wonderful to meet so many people and share experiences.

I loved being able to communicate with other patients, forming bonds and making friends, while learning so much.

Amazing, memorable, overwhelming, and priceless. Exhausting, but worth it. Life changing.

I loved the people sharing stories, support, fears, feeling understood and NOT crazy.

Supportive, energizing and fun. Great to know there are people that know and care about us. The Association is wonderful!

I left the conference feeling hope for the future.

Practical information presented in non-technical language.

My husband came with me this time, and that was great. I wanted him to hear all the information and he listened and took notes with interest.

Life changing. My whole life will be "before the conference" and "after the conference."  
Always overwhelmed, and love it!

As an RN for forty years, mainly ICU and dialysis and Home Care, I have been to many conferences. This was great...just keep doing what you are doing! It was very informative.



We are pleased to announce the next round of regional meetings for hypoparathyroidism patients! These regional patient meetings are **free** one-day events for hypoparathyroidism patients and caregivers. These meetings are sponsored by an educational grant from NPS Pharmaceuticals.

Each NORD patient meeting begins with breakfast and then a two hour presentation from a physician expert. The presentation by the physician expert is the central point of the meeting, and the interactive dialogue/Q&A has been proven to be very valuable to attendees. After lunch, the Hypoparathyroidism Association will present on the available resources they provide for patients and caregivers. We will also highlight one patient's journey with the disease.

In the afternoon session, patients and caregivers are separated into different breakout groups in order to discuss their respective issues in a supportive setting. These breakouts provide a private setting to share common concerns, fears and challenges and to learn from one another. There is also time to discuss some of the issues associated with the disease, such as the sense of isolation, challenges of being a caregiver of a patient, chronic disease management, coping strategies, etc.

Each meeting provides a highly-interactive setting for patients to learn and to be better prepared to deal with the challenges of their disease. But most importantly all participants leave as a member of a supportive community.

For more information, please see the [HypoPARAthyroidism Association](http://www.hypopara.org) website.

## UPCOMING MEETINGS

Saturday, August 23, 2014 – Atlanta, GA

Friday, October 3, 2014 – Tampa, FL

Friday, October 10, 2014 – Phoenix, AZ

To register go to: <https://events.rarediseases.org>

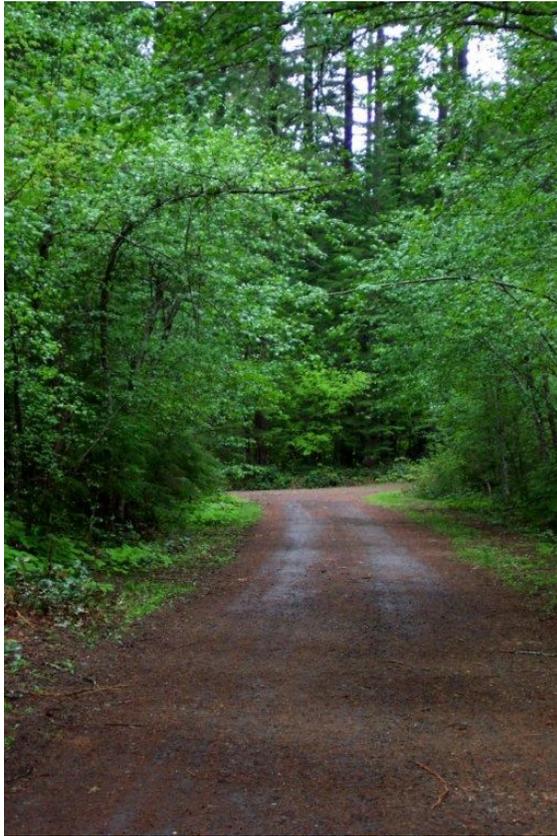
**Each patient will receive a small stipend to help defray travel costs.**

**If you have further questions not answered by the brochure, please do not hesitate to contact NORD with questions concerning this event at 203-744-0100 or [HYPXmeetings@rarediseases.org](mailto:HYPXmeetings@rarediseases.org)**

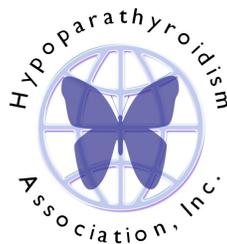
**The HypoPARathyroidism Association** is an independent non-profit organization devoted to helping those with **ALL** forms of hypoparathyroidism, a rare medical disorder in which the parathyroid glands fail to produce sufficient amounts of the parathyroid hormone. The Association is directed by an unpaid volunteer Board of Directors and is overseen by a Medical Advisory Board.

**Our Mission is to:**

- ◆ ***Educate** the public and professionals about hypoparathyroidism*
- ◆ ***Communicate** through our quarterly newsletter, website, and other social media*
- ◆ ***Support** patients, their families and care givers with information and emotional support*
- ◆ ***Fundraise** to support research for a cure*



James Sanders



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