The HypoPARA-Post
Improving Lives Touched by Hypoparathyroidism

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Disclaimer Statement

The Hypoparathyroidism Association, Inc. should NOT be used as a substitute for professional medical and psychological treatment. Any suggestions we may offer in our quarterly newsletter, on our website, or in any e-mail correspondence should be considered as ‘suggestions’ only. Any changes in your current medical treatment you may want to consider should be discussed with your personal physician and should NOT be undertaken without his/her concurrence and support to ensure proper medical treatment and follow-up.

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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Many things have occurred in the Hypopara world since the last newsletter.

Several members of the HypoparaTHYroidism Association, including three Board Members, traveled to the University of Maryland to testify before the Medical Advisory Committee to the FDA, which is considering the approval of Natpara. It turned out to be an interesting and informative event for those of us who participated with live testimony and who were able to submit their testimony in print form. The decision rendered at the conclusion of the hearing was 8 to 5 in favor of recommending the approval of Natpara.

Our story is included in this newsletter. We made a difference! How much? Only time will tell.

All of us had to anxiously wait for the “FINAL” decision of the FDA, which they were to make on October 24th. Within days of the hearing in September, the many Face Book groups were filled with positive comments and expressions of hope, which became more fervent as the magic date drew closer.

Then on October 23rd, a day early, the FDA announced they would put the “FINAL” decision off until January 24, 2015. Of course, their decision crushed us and we entered into a new and longer holding pattern to allow the process to go forward. We were disappointed, but accepted the reality. We have waited several years for the FDA to approve a hormone replacement treatment for hypoparathyroidism, and we have accepted the fact we will have to wait another three months.

A couple years ago, we began holding a Silent Auction at our yearly conferences to help raise funds for hypoparathyroidism research. Because it has not seemed fitting simply to call it The Hypoparathyroidism Research Fund, we have decided to call it The Billy Sanders Research Fund for Hypoparathyroidism or “Billy’s Fund” for short.

Billy was my older brother who died of hypoparathyroidism before I was born. My brothers, all five of my sons and I subsequently have been diagnosed with hypoparathyroidism.

Billy’s Fund will help ensure researchers have the means to do continuing research into hypoparathyroidism. It is a fitting tribute to Billy, who never had a chance at life. See page 6 for the current information on the fund.

Speaking of our conferences, we continue preparations and planning for the 9th International Conference on Hypoparathyroidism, to be held June 4-6, 2015, in Minneapolis, Minnesota. We are almost there, and it promises to be our largest and best conference ever. We hope each of you will make plans to be there. You will not be disappointed.

The Volunteer Advisory Committees are coming along, as several of you stepped up to volunteer where your skills and talents could be put to the best use. We need more volunteers if the committees are truly to become a viable force for the future of the hypopara community. All of the committees can use a few more volunteers. You can find the application to volunteer on our web site under ‘Volunteer’; just email it to the address on the application.

Dr. Kim has reviewed another article on hypoparathyroidism. This time she is reviewing the article just released on the PARADOX Study, which many of you participated. A copy of the original article on PARADOX is available on our website so you can take a copy to your doctors. Her insights, both as a post-surgical patient and as a physician has helped me understand the medical papers she has reviewed. They have enhanced our education and understanding about hypoparathyroidism. Thank you, Dr. Kim, for writing them for us.

Tommy Ravnic has launched HypoPARA Australia for hypoparathyroidism patients in Australia. The story of HypoPARA Australia in this newsletter. Tommy’s story will appear in the next newsletter.

Enjoy this edition of The HypoPARA Post. It is your story.
Summary and Review of PARADOX Study by Nandini Hadker, MA; Jacqueline Egan, BA; James Sanders, BA; Hjalmar Lagast, MD; Bart L Clarke, MD

Original Article: Understanding the Burden of Illness Associated with Hypoparathyroidism Reported Among Patients in the PARADOX Study [Editor’s note: you may obtain a FREE copy of the complete article courtesy of the AACE on our website at https://www.hypopara.org/webinars/paradox_results.html ]

I, like most of the entire hypoparathyroidism (HPTH) community, was excited to see the recent PARADOX study published earlier this summer. It is my privilege to summarize and review it. As in prior reviews, I will first summarize the actual study itself, and at the end will provide my own commentary on the significance and future impact I see this study having, from both a patient and physician perspective.

BACKGROUND:
HPTH is a rare, complex endocrine disorder characterized by absent or inappropriately low levels of parathyroid hormone (PTH), resulting in imbalances of multiple minerals, including low calcium, high phosphorus, and decreased ability to convert vitamin D to activated vitamin D (which is needed to absorb calcium from the gut). HPTH patients experience multiple symptoms and long-term complications from the disease, but the impact on quality of life and psychological burdens from the illness have not been well-studied previously. At an International Workshop on Hypoparathyroidism, it was reported that patients noted “highly subjective and variable descriptions of disease-associated symptoms.” Yet, it has been reported in a small questionnaire-based study that females with post-operative HPTH had clinically relevant impairments in mood and sense of well-being compared to a control group of females who had intact PTH function following thyroid surgery. This impact on quality of life was present in the HPTH females even despite stable calcium and vitamin D treatment, suggesting that findings may be a direct result of PTH deficiency.

This study reports the findings from the Patients’ Attitudes and Responses About Hypoparathyroidism Teleration Explored (PARADOX) study, which was a cross-sectional (performed at one time point) patient survey that sought to quantify the burden of illness associated with HPTH.

METHODS:
Patients included both male and female subjects, at least 18 years of age, residing in the U.S. HPTH was diagnosed by a physician at least 6 months prior to the study. Patients with pseudohypoparathyroidism or pseudopseudo-hypoparathyroidism were excluded. Patients were included only if they reported low serum levels of calcium or use of medications used to manage low calcium levels. Subjects who were currently or previously enrolled in HPTH clinical trials were included. Subjects were recruited through the Hypoparathyroidism Association and social media forums.

The study design was a web-based survey in which patients self-reported answers to a nonvalidated ~30-min questionnaire. The questionnaire was subdivided into topic areas of screening eligibility, demographics, diagnosis, and management; initial perceptions, current symptoms, perceptions, and therapy; acute episodes and comorbidities; and impact of disease on employment, personal and social life, and well-being. A 7-point scale was used to grade responses, where “1” equaled “strongly disagree” or “not at all satisfied,” and “7” equaled “strongly agree” or “extremely satisfied.” Disease severity was self-reported as “mild,” “moderate,” or “severe,” with no specified definition or description of severity grades given on the questionnaire. Symptoms experiences in the last 12 months were selected from a list of 38 itemized symptoms, categorized into physical (25 symptoms), cognitive (7), and emotional (6). Co-morbidities were selected from six medical conditions, and current medications were selected from 11 therapies. Impact of disease was also graded on a 7-point scale, where “1” equaled “no interference” and “7” equaled “significant interference.”

Once the online questionnaire was completed, eligibility criteria were checked for inclusion before being included in the analysis. Data gathered were analyzed by overall population, sex, cause (surgical or other), and disease severity (mild, moderate, or severe). Findings presented in this study focus on the overall population and disease severity.

RESULTS:
A total of 387 patients completed the questionnaire online between June 13 and July 23, 2012. The final analyzed data set included completed questionnaires from 374 patients, with 13 patients excluded due to not having hypoparathyroidism diagnosis. Average age of patients was 49.4 years, with 85% female. The majority (78%) of patients had postsurgical cause of HPTH, with 43% having undergone surgery for cancer. Nonsurgical causes comprised 22% of patients. The breakdown in severity of HPTH was: 21% mild, 48% moderate, and 30.5% severe; there was no statistical difference between how many females vs. males reported a given severity. Average duration of HPTH condition was 12.6 years, though a substantial number (44%) were between 4-10 years since HPTH diagnosis.

Healthcare Provider Interactions
The HPTH diagnosis was made by an endocrinologist in 51% of patients, by a surgeon in 25%, and the rest by a
primary care physician (PCP) or other specialist. Patients saw an average of six different physicians for evaluation of their symptoms before and after their HPTH diagnosis, and more than 60% had seen four or more physicians. The majority (98%) of patients were currently having their HPTH managed by a healthcare provider; 72% by an endocrinologist and 21% by a PCP. Patients reported seeing their managing physician an average of four visits per year.

**Patient Perceptions and Attitudes**

At diagnosis, 56% of patients strongly agreed that they felt unprepared to manage their condition, with 48% strongly agreeing with feeling mismanaged initially. A majority (60%) of patients strongly agreed that controlling their HPTH was harder than they expected, and 79% strongly agreed that most physicians do not understand HPTH. Despite cycling through multiple physicians, 11% were unsatisfied with their current managing healthcare provider, while 50% reported being extremely satisfied.

**Medications**

The majority of patients (68%) were taking more than one medication, and 59% were taking >4 pills/day. The vast majority (92%) were taking calcium either alone or in combination with vitamin D. Forty-four percent of patients were taking active vitamin D (i.e., calcitriol). Fifteen percent were on any form of PTH (i.e., 1-34, 1-84) through clinical studies, and 2.7% were on teriparatide (i.e., Forteo®). The majority (67%) of patients reported 3 or more blood tests to monitor their calcium levels in the last 12 months, and 34% reported 6 or more blood tests in that same time period.

**Ongoing Clinical Symptoms and Comorbidities**

Patients reported experiencing an average of 16 physical, cognitive, and/or emotional symptoms, with 72% experiencing >10 symptoms. Those with moderate or severe disease experienced an average of 16 and 19 symptoms, respectively, whereas those with mild disease experienced an average of 9 symptoms. Females were significantly more likely to report more symptoms than males. On average, patients reported having symptoms for 13 hours per day, with postsurgical HPTH patients experiencing symptoms for a longer duration during the day (average 13 hours) than nonsurgical HPTH patients (average 11 hours).

The physical, cognitive, and emotional symptoms reported by surveyed patients in the last 12 months despite current medications is summarized in the below Figure 2 from the PARADOX article. The majority of patients experienced physical symptoms of fatigue (the #1 reported symptom at 82%), muscle pain/cramping, numbness/tingling (a.k.a. paresthesia), tetany, joint or bone pain, and pain/heaviness/weakness in extremities. The majority of patients experienced cognitive symptoms of brain fog, difficulty concentrating, memory loss, and sleep disturbances. Emotional symptoms experienced by over 50% of patients included anxiety/fear/inner unrest and feeling sad/down/blue/depressed. For each of the physical symptoms, the incidence was significantly higher in patients with moderate or severe disease compared to

<table>
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<th>Physical (25 symptoms)</th>
<th>Cognitive (7 symptoms)</th>
<th>Emotional (6 symptoms)</th>
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<tr>
<td>1. Fatigue 82%</td>
<td>1. Brain fog/mental lethargy 72%</td>
<td>1. Anxiety/fear/inner unrest 59%</td>
</tr>
<tr>
<td>2. Muscle pain/cramping 78%</td>
<td>2. Inability to focus/concentrate 65%</td>
<td>2. Feeling sad/down/blue/depressed 53%</td>
</tr>
<tr>
<td>3. Paresthesia 76%</td>
<td>3. Memory loss/forgetfulness 61.5%</td>
<td>3. Emotional sensitivity 47%</td>
</tr>
<tr>
<td>4. Tetany 70%</td>
<td>4. Sleep disturbances 57%</td>
<td>4. Feeling misunderstood/not understood 44%</td>
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<td>5. Joint or bone pain 67%</td>
<td>5. Inability to think through a complicated task 41%</td>
<td>5. Hyper irritability/being hypercritical 36%</td>
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<td>7. Disturbance to bowel movements 46%</td>
<td>7. Delirium 5%</td>
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<td>8. Brittle nails 44%</td>
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<td>9. Heat intolerance 44%</td>
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<tr>
<td>10. Headaches 42%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Damage to skin/extreme dry skin 40%</td>
<td></td>
<td></td>
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<tr>
<td>12. Cold sensations 37%</td>
<td></td>
<td></td>
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<td>13. Hair loss 33%</td>
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<th>Clarity of Medicine</th>
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<td>Clarity of Evidence</td>
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Fig. 2. Symptoms experienced by patients in the last 12 months. Patients indicated from a checklist the physical, cognitive, and emotional symptoms they experienced in the last 12 months despite taking prescription medications. Shading reflects symptoms experienced by ≥50% of patients.
those with mild disease.

Regarding comorbidities and acute episodes, 69% experienced comorbidities, with the most frequently reported ones being heart arrhythmias (66%) and kidney stones (35.5%). There were 79% of patients who reported hospital stays or emergency department (ED) visits, with the average number of reported lifetime ED visits of 6. Complications/comorbidities and ED visits were higher in those with severe disease compared to moderate or mild disease, and length of hospital stay was also longer for those with severe disease. The annualized rate of ED visits or hospital days for HPTH patients were higher than the national average for the general population.

**Impact on Employment, Personal and Social life, and Well-being**

Significant interference with overall quality of life due to HPTH was reported by 45% of patients; this was considering all aspects of their condition over the preceding 12 months. Over the course of their diagnosed lifetime, there was a decline in the number of HPTH patients who reported full- or part-time employment status (68% before diagnosis vs. 58% after), and more patients reported being disabled (4.5% before vs. 14% after), retired (6% vs. 10%), or unemployed (1% vs. 5%). Of 18 patients who were currently unemployed, 72% attributed their status directly to their HPTH. Of those who were employed, HPTH patients had an average of 6 absentee days per year, and an average of 65.5 days during the last year where they were unable to perform at their full potential.

For 85% of patients, HPTH prevented them from performing activities normally done around the house, with a daily or weekly limitation reported by 62%. Close to a third of patients reported significant interference with various social and personal relationship abilities (e.g., ability to socialize, entertain company, travel, intimacy, etc.) and with their well-being (e.g., quality of sleep, being able to manage stress, emotional well-being and mental ability). The majority (72%) strongly agreed that it is difficult for family and friends to understand their condition.

**DISCUSSION/COMMENTARY:**

The PARADOX study is the largest study to date of HPTH patients examining the clinical implications of HPTH, including impact on multiple psychosocial aspects of a patient’s quality of life. The findings revealed a broad negative impact of HPTH on overall quality of life, with a large burden of medication use, frequent serum calcium monitoring, and multiple physical, mental, and emotional symptoms on a regular and persistent basis. These findings emphasize the long-term consequences of living with HPTH despite current treatment options, and the large unmet need of better therapies to improve symptoms and quality of life in HPTH.

Patients with self-described moderate to severe disease had a greater number of different symptoms, more occurrences of symptoms and acute episodes, as well as more clinical complications and comorbidities, compared to those with self-described mild disease. The difficulty with studying any rare disease like HPTH is that until a study like this has been performed, it is not possible to have a “validated” questionnaire or “definitions” of mild, moderate, or severe disease. The results from this study will likely serve as a good reference from which other investigators may start to classify HPTH study subjects into varying levels of severity, depending on the burden of symptoms and complications.

There were some limitations of this study, including the self-reported nature of the survey answers. Since patients were recruited from the Hypoparathyroidism Association, a volunteer-run patient support group, it is possible that survey participants were more likely to report more symptoms than the general HPTH population. However, the large number of HPTH patients included in the survey underscores the unmet needs of a substantial portion of the HPTH population. This study did not verify whether the postsurgical HPTH patient’s thyroid status was optimally managed, so some of the symptoms reported may have overlapped with suboptimal thyroid hormone balance as well. Finally, there was limited data on monetary impact, so conclusions could not be made regarding the burden on healthcare utilization costs, etc.

However, the PARADOX study is a landmark study, as it describes in detail, for the first time in a large population of HPTH patients, the patients’ perceptions of overall impaired sense of well-being, many daily and prolonged clinical symptoms, how poorly their healthcare provider(s) understand their condition, and difficulty with family and social life. There is an “empathy gap” between patients and many physicians, where although the HPTH patient “looks well” and their serum calcium numbers may be “in range,” multiple symptoms persist, likely due to the underlying lack of PTH itself. In my opinion, these insights should now be disseminated widely to the healthcare provider community at large, with specific physician groups targeted first and foremost: endocrinologists and endocrine surgeons. Ultimately, all physicians, including PCPs, should be educated on the burden of this illness, but since endocrinologists and endocrine surgeons are the providers most likely to assume short- and long-term management of the condition, it is critical that all such specialists are aware of the impact of this disease on a patient’s life. This has the potential to fundamentally change many doctor-patient interactions, as many endocrinologists and surgeons are simply unaware of how burdensome HPTH really is. Many physicians believe that it is “easily treated” by taking calcium/vitamin D supplements, and often, symptoms are dismissed by the doctor as long as the calcium level is within an acceptable range. Indeed, it has recently been shown that the impact of postoperative hypoparathyroidism on patient quality of life is consistently and significantly underestimated by surgeons and subjects receiving surgical consultation (see Chon et al, *Endocr Pract.* 2014 May 1;20 (5):427-46).

Future directions of research from this study’s findings, some of which may already be ongoing, include new and more effective treatment options for HPTH, quantifying the health economic impact of the disease, and including specific symptom, muscle function, and quality of life measures as outcomes in treatment studies. Other research efforts I would hope to see include studies in postsurgical HPTH patients attempting to ascertain which symptoms are associated more
with unstable calcium levels vs. thyroid levels over time; studies assessing the possible need for at-home calcium meter use so that HPTH patients could potentially improve their quality of life by having a self-titration method of calcium dosing, akin to diabetics using a sliding-scale insulin for intermittent high glucose readings; and improved methods of PTH delivery other than injections. Ultimately, stem cell research with the hopes of growing “new” parathyroid tissue is promising, but that will likely take a very long time to become a reality in clinical practice. We eagerly await the FDA decision on Natpara (PTH 1-84 hormone replacement therapy), and if this gets approved in late October 2014, then future studies of Natpara users should also examine the impact on all the domains of quality of life assessed in the PARADOX study.

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Billy’s Fund

As Jim explained in his column, we now have a name for our research fund.

Billy would be proud! There is now over $9,000 and counting. Of course we need a lot more money before we can start helping with research.

Each quarter we have been giving suggestions on how you can help and this quarter we have a member, Cheryl, who has set up an automatic monthly contribution to the fund. She also asked her employer to match her contributions. Over the next year, she and her employer will be contributing $2,000! Imagine how much we could raise if everyone, who can, did this!

Thank you Cheryl and everyone who has helped so far!

This fund will go a long way to helping others like Billy and you.

Having the medical community better understand and, dare we envision, a world where hypoparathyroidism can be treated and even in some cases eliminated, is the goal of this fund.

Funding cuts are threatening to severely reduce further research into hypoparathyroidism. We as a community need to unite and help ourselves and others by finding ways and means to providing for research into hypoparathyroidism.

If you have a great idea for fundraising, then let us know and we will put it out there. You never know, you may be sitting on a great idea along the lines of the ALS ice bucket challenge!
Considerations for Your Hypoparathyroidism Treatment

When Speed Matters
Cal-EZ is just calcium and vitamin D powder, that’s it. In a clinical study Cal-EZ was shown to absorb FASTER and more efficiently than a calcium citrate pill.

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<th>Easy to Use</th>
<th>Easy to Absorb</th>
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<td>Cal-EZ can be easily blended into beverages or mixed into food without altering taste or texture.</td>
<td>Cal-EZ comes with vitamin D built in to improve absorption.</td>
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<td>The convenient, waterproof sleeves allow you to have calcium with you all the time, anywhere.</td>
<td>As a powder, Cal-EZ doesn’t contain binders or fillers like chewables or tablets do, making it much less work to digest.</td>
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An easy way for you to get your daily calcium

When compared in a study with a single serving of a leading calcium citrate tablet, a single serving of Cal-EZ
- Resulted in greater absorption
- Was absorbed more rapidly

Learn more at www.Cal-EZ.com

Receive a FREE one-month supply of Cal-EZ!

Join our mailing list at http://goo.gl/oBsmG5 and we will mail you a one-month supply of Cal-EZ.

By registering, you will be included in future mailings for Cal-EZ. Your information will not be sold or distributed.
When you are given a diagnosis of Hypoparathyroidism (HPTH), you become very familiar with calcium and activated vitamin D like Rocatrol (Calcitriol), the preferred medications approved by the Food and Drug administration (FDA) to help maintain calcium levels.

Unfortunately, taking both activated vitamin D and calcium in the quantity that many have to take them to maintain their calcium levels means two seemingly benign drugs may have some unpleasant, long-term effects on the body.

The last few years there has been testing on a new drug that won’t simply put a band-aid on the issue but might be a better solution to the needs of Hypoparathyroidism patients. Natpara (1-84) is a synthetic intact parathyroid hormone developed by NPS Pharmaceuticals. After much testing it is now up for approval by the FDA to be used as treatment for HPTH. The FDA currently did approve the drug Forteo (1-34), a fragment of the parathyroid hormone. It is approved for use in women who are prone to bone breaks from osteoporosis. But, using it for treatment of HPTH was not possible outside of clinical trials or if a doctor would prescribe it “off label”. Natpara, which represents the whole parathyroid hormone (PTH), should be an even more effective choice for those without sufficient PTH.

Last month, several people from the HypoPARAthyroidism Association were given the opportunity to share their story with the FDA as it decides whether to approve this new drug treatment. James Sanders, founder of the HypoPARAthyroidism Association, testified first and fourteen others followed him addressing the FDA panel. Below are James Sander’s testimony and a sampling of others.

These fifteen people got to share their stories with the FDA and by doing so they made a difference in the lives of us all.

James Sanders-Founder of the HypoPARAthyroidism Association

“If I had known what my life would have been like with hypoparathyroidism I would have chosen to live with thyroid cancer.”

I’m the founder of the HypoPARAthyroidism Association, and that’s what I’ve heard from some patients.

My name is James Sanders. NPS Pharmaceuticals is reimbursing me for my travel to come here to testify today, but the testimony I am giving is mine, and that of the HypoPARAthyroidism Association.

I’ve had hypoparathyroidism for the last 58 years. I had to learn how to deal with my symptoms on my own.

Tetany is the most common symptom, but only one of the symptoms hypoparathyroidism patients have to deal with every day. There are 38 and counting, which were only just recently described in the PARADOX Study published in May. This information will enable physicians to make a diagnosis of hypoparathyroidism much quicker than before. This is an important step forward since many patients feel that no one understands why they are sick.

Conventional treatment only allows physicians to manage hypoparathyroidism with the potential of eventually damaging the kidneys. Natpara offers patients and their doctors another, more effective method of treating HPTH.

It’s an important issue. Here’s how a couple of hypoparathyroidism patients I know describe their lives with the disorder in just six words:

“A rollercoaster ride without the thrills.”

“Hang’n outside the box, upside down.”

Many patients, especially postsurgical patients, have seen their lives turned upside down, leaving them with few choices. I am aware of some patients who find themselves needing calcium by IV several times a week, and it is all they can do to maintain their calcium level.

Their family and their friends do not understand hypoparathyroidism, and often feel they are faking it because they “do not look sick”. One patient discovered he had hypoparathyroidism when his calcium level “crashed” while he was driving a car on a Pennsylvania Freeway. Luckily, for him, his twelve-year-old daughter was able to help him get their car safely to the side of the road.

The biggest price many of us have to pay for having hypoparathyroidism is finding our career paths cut out from under us. I struggled for years at my job as a radiation control technician, and retired early. Brain fog and other cognitive symptoms contributed to a loss of my mental ability.

Perhaps what is most disturbing to me are the patients who have given up on their dreams, or their careers.
It is my hope, and the hope of the Hypoparathyroidism Association, that Natpara will make a difference in the lives of patients throughout the United States. All we are looking for is a sense of normalcy in our lives, and barring that, just a relatively ‘normal’ life in spite of hypoparathyroidism.

Thank you.”

Carol Sanders—Wife and Mother of HPTH sufferers

“I know hypoparathyroidism. I am the wife of a patient and the mother of FIVE. All are idiopathic. I also answer the HypoPARAthroidism Association’s phones. Therefore, I talk with hypoparathyroidism patients every day. I know that there is no such person as a stable hypoparathyroidism patient, even if they are using the traditional treatment of calcium and Vitamin-D to manage their symptoms. Their calcium levels can drop at a moment’s notice due to the stress of everyday life. Stress in any form, good, bad, happy or sad, physical or mental or emotional, can cause their calcium levels to drop very quickly. They are unpredictable and they are unstable - the faster the fall, the harder the fall. They cannot come back from a ‘crash’ without medical intervention, whether they take an extra calcium pill or a trip to the ER for a calcium infusion.

They also are concerned about the soft tissue calcifications, their kidney function, cataracts, and bone issues.

They are trading today’s management for tomorrow’s health issues.”

Cathy Campbell

“To those who cannot fathom living with Hypoparathyroidism, I use the analogy of needing to maintain an absolute steady-state temperature in a room with a non programmable thermostat. To do so would require constant and accurate monitoring of the room’s actual temperature. It would also require a heating/cooling system that could deliver rapid responses to bring the temperature in line with the required level. At least in this scenario, you have the benefit of being able to determine the room’s actual temperature.

With insufficient hypoparathyroid hormone, there is no way to know what your serum calcium is at any given moment. Sadly, there is no portable test such as diabetics use to monitor their blood sugar. The only way to know your level is low is when you become symptomatic for hypocalcaemia. Some people don’t experience severe enough symptoms that they realise they are hypocalcaemic. Given the length of time for the body to metabolise calcium, by the time you are symptomatic, you are hours away from relief.”

Cathy Poole

“I implore you to approve the use of Natpara, Recombinant Human Parathyroid Hormone for those of us suffering with the dreadful symptoms of hypoparathyroidism.

To avoid losing my full time benefits and salary, I am using all vacation days and sick leave to work 4 days weekly as a medical practice manager.

I serve on the board of directors for an environmental group, North Carolina Alliance for Transportation Reform, but no longer attend meetings. I am past president of Greater High Point Medical Managers Association and worked as an adult literacy tutor at High Point Public Library as my service project for Altrusa International of High Point.

My elderly parents need my help as their POA (power of attorney) and loving daughter.

I miss gardening and riding Tennessee Walking Horses with my niece and working at the barn for relaxation.

I am 57 years old.

I hope that with Natpara PTH replacement therapy, I can once again contribute to society and enjoy more time with my family, friends and colleagues.”

Kim Whisenant

“I have suffered with hypoparathyroidism since the removal of all of my parathyroid, incident to my thyroidectomy in 1977.

I have experienced much suffering over these many years due to this condition. A part of the problem is the ignorance of most medical professionals about this condition. Even many endocrinologists do not have a good understanding of the proper treatment.

Due to improper treatment, I have suffered through a long term Rocal-trol over dosage, bone spurs, and kidney stones. When I had the original surgery for my thyroid, I spent 6 weeks in the hospital while they attempted to stabilize my calcium. This left my little one-year-old daughter without her mother for 6 weeks and then she suffered months and months of sub-par mothering from me due to my still unstable calcium levels.”

After the testimonials Mary Frances Harmon, head of Global Patient Advocacy for NPS, told everyone “We cannot thank you enough for your courage and selflessness in sharing your very personal and moving stories in order to help others that you don’t even know! Your testimony was impactful, moving and made a difference in encouraging the panel to provide a positive recommendation to
to approve Natpara. On behalf of NPS Pharma, I thank you from the bottom of my heart!!”

The advisory medical committee, after some discussion, voted 8 to 5 to approve Natpara as a treatment for Hypoparathyroidism. The original date for the final vote on NATPARA was October 24, 2014; it was resched-

uled for January 24, 2015.

Thank you to James Sanders and the others who took the time and effort to ap-

pear before the FDA committee and share your stories.

Thanks also to all of you who wrote let-

ters or emails, encouraging the commit-

te to vote yes. Not enough is known

about our disease and approval would have never happened if it wasn’t for you all sharing your stories letting the members of that committee know ex-

actly what Hypoparathyroidism does to a person and their family.

Having this new drug treatment will change the lives of so many. Thank you!
Beating Hypoparathyroidism: My Path to a Full Ironman

By Josh Becker

It all begins in the year 1982. I was diagnosed with a bi-lateral hearing loss. At the time, my diagnosis was Moderate to Severe Hearing Loss. Shortly after my diagnosis, I received my first set of hearing aids. Fast-forward about six years, where I am about eight years old in the third grade. I recall complaining about my fingers hurting, so my mom decided to take both my sister and I into the doctor for routine blood work. The needle did not bother me, of course my sister hated every minute of it. The labs came back a few days later and my doctor thought there might have been a mistake at the lab due to the low calcium reading they received on the first draw. They retested of both us, and my calcium came back around 4.6, which we know is very deadly.

In 1988, my life changed drastically after being diagnosed with Hypoparathyroidism. However, just because I had this disease it was not going to take my fun and enjoyment out of life away from me. I have always been very active whether it was Soccer, Gymnastics, Biking, Basketball, Martial Arts. I did go through the typical rebellious stages when I hit my early teen years - my doctor warned my parents about this happening. I stopped taking my medication for about 3-1/2 months because I hated it and thought the doctors were lying to me. Low and behold, it hit me hard, I got pretty sick and depressed and eventually I confessed about not taking it. I was in my late teens before I understood how to actually pronounce hypoparathyroidism.

One of the hardest battles was actually learning to accept my disease, and I knew I needed to deal with the pain at some point in my life. I was in my early 20’s when I sought out some therapy and one of the first things we dealt with was my disease. I came to my therapist one day after work, brought a baggy of about 30 pills, threw them on the table, and cried like a baby. (Even today, I still get emotional about this). One of the most difficult things in life is accepting you have a disease and there’s nothing you can do to change it or even fix it. I did learn one thing that day, I might have Hypoparathyroidism, but I do have a choice. Either I let it control me and whine about every little thing about it, or I grab life by the horns and say: “you know what, I have a disease but it is not going to get in my way of anything in life - I want to enjoy my life and live it at its full potential.” - I chose the latter!

Fast forward to the year 2006, I started to have a few health issues, I had gained a lot of weight, and I decided to check in with a doctor. I found out I had some severe food allergies, so I started to drop some weight and I changed my diet. Over the course of five months, I managed to drop about 60 pounds, and that is when my life changed forever. I decided I wanted to start running and riding my bike further distances and perhaps maybe do some races. I see my endocrinologist twice a year and I talked to him about my wanting to get very physically active and doing some training for races. He said I was perfectly healthy, to watch my electrolytes, and drink plenty of water. I started running about a mile at a time, slowly increasing my distance when I felt comfortable with it and the same happened with my biking. In summer of 2007, I joined a local running store and trained for the 2007 YMCA Turkey Trot in Dallas, TX. There are two options and I chose the 8-mile option. It was my longest distance to attempt ever. I finished in 1 hour 15 minutes - that was my first major accomplishment. I had another race a few weeks later in Dallas with my job. We had a relay to do at the Metro PCS Dallas White Rock Marathon. I was only riding a hybrid bike at the time, which is a cross between a road bike and a mountain bike. In January 2008, I got my first road bike from my dad as a birthday gift. Later on that year, I joined up with Team in Training and raised money for The Leukemia and Lymphoma Society and part of the return was an entrance to my first sprint distance triathlon in Austin, TX. I did one other small sprint distance triathlon before this but it was a shorter distance. I learned so much from my race in Austin, TX. For those who are not familiar with what a triathlon is, it consists of three disciplines - swimming, biking, and running, typically always in that order. Swimming is my hardest discipline; it requires a lot of muscle movement and lots of training. I had issues with my goggles in the swim, then I bonked on the bike ride. (Bonking is a term
used where you are out of energy). I just did everything I could on the run to finish my first major race.

Being extremely physically active can have its drawbacks as well. Not just for people like me who have Hypoparathyroidism but just everyday people. The drawbacks are injuries. Everyone gets them, however from my experiences, it seems like it does take the average person a lot less time to recover then it does for me. I suffered a few injuries in the beginning of my training six years ago. I had issues with a bone in my foot that required special insoles in my shoes, which caused major issues for me in other ways. Those issues meant other injuries or severe blisters. One thing I do not recommend anyone doing is wearing brand new combat boots for a 10 Kilometer Mud Run. I suffered greatly for that, I could not wear shoes for a month because of blisters on the back of my heels! One of the biggest differences between my beginner races and now, is I am no longer on Rocaltrol (Calcitroil) I am on the PTH-1-84 (NatPara) injection. The biggest learning curve of being an athlete is getting to know your body. All athletes are competitive in our own ways, sometimes that competitiveness gets ahead of our brains and we can cause ourselves more harm than good. I always listen to my body now. I will not make the same mistake I made in 2009 while training for my first half marathon (13.1 miles). I managed to break a small bone in my big toe, and I did not stop training I worked through the pain. I never allowed my foot to heal properly. My training stopped at ten miles, so the last three miles were on my own. Finishing this race was a big deal! I actually do not think I will be able to match that time again, but I will attempt to in the future. (Two hours, Five minutes). I ran another Half Marathon in 2010 as well but finished slower, I was dealing with many injuries. Because of the toll on my foot from breaking it, I was not able to do another half marathon in 2011. For both 2011 and 2012, I participated in my Triathlon Team Race for Sprint Triathlon, both of which I finished under two hours. I did one other sprint race in 2012, but bonked badly in the run. In spring of 2013, I had surgery on my foot and took most of the season off - just did some easy running but continued to bike. That brings me to 2014.

In December 2013, I decided it was time for me to start pushing towards my goal of completing a full Ironman. I signed up for my first Half Ironman 70.3. The year 2014 has been the busiest training season I have had yet! One of the first races I did this season, which I hope I can do in February 2015, is the Dallas Hot Chocolate Run! They do this race all over the country. It’s a lot of FUN! Shortly after that run, I had a slight setback in running; I had purchased some new shoes to go with the custom insoles I had made since I had foot surgery. It turned out the custom soles were causing me more injury then good, so I had to learn how to run all over again over the course of about a month or so. I also did a bike rally (large gathering of cyclist for a bike ride) in Muenster, TX - that was one of the most difficult bike rides I have ever done, but it was part of my training for a Half Ironman. About a month or so after that, I had my Team Long Distance Training camp in Arkansas. I was not nearly as ready as my fellow teammates for the distance, but it definitely prepared me very well for the months ahead in my training, mentally and physically. In July, I had my first Olympic Distance race in Waco, TX in the heat. One of the key things I implemented in my training was focusing on the heat because I knew there was a chance Austin was going to be hot. My coach and I learned that it isn’t a good idea for me to do any practice the day before the race; my muscles tend to crank up from tension. I had a great swim going into my race on Sunday; however, my race was over when I flattened out ten minutes into the bike. I had some major issues changing my flat tire, and that pretty much ended my race. I continued on the course but ended up with a DNF (did not finish) because I was over the course limit for my wave. It’s always good to have training races, big or small, to prepare for your main race. This is when you can try out new things to find out what works and what does not work. I was upset with that race, so my coach and I decided that we would schedule one more race before my Half Ironman in Austin, TX. It was going to be a busy month for me in September. I had my first 20K race in a few years and it was a very
successful race for me - I felt great afterwards! Then just a week later I would have my last Olympic Distance race in McKinney, TX and I had an awesome race. Everything for that race followed my race plan, and I felt great.

Fast-forward about four weeks and that puts you at my Half Ironman in Austin, TX. I felt very ready and prepared for the race. My truck was parked at the hotel and I had my usual pre-race breakfast – one BIG sweet potato with grass fed butter and cinnamon, along with a side of fresh berries. I had a lot of time to kill in the morning before my swim wave began, as I was at the end of the pack starting at 8:40am. Sooner than later my time came to start the race, I was nervous yet I was also very calm. My swim started out very well, but unfortunately, around the second half of my swim I started to experience cramping in my legs, I would have to alter how I was swimming to avoid the cramp in my hamstring. Then I finally make it to the swim exit, and I realize on my watch I am way behind my schedule, it put me in slight over-drive mode, but I knew I still needed to remain calm. As I walk towards the exit, my right calf starts to cramp up and I am grabbing my leg trying to get it to calm down. I make it through the exit into my transition, and then I experience two charley horses in both legs in a matter of seconds. I knew this was going to be a race I was going to have to give it everything. I could hear my sister screaming my name and telling me to go and cheering me on - I shooed her off and told them to go to the shuttle. Now, on to the next part of my race - 56 miles on the bike, my estimated time is about three hours, depending on the conditions I have and the winds. Since I had the cramping in transition, I knew I needed to loosen up my legs and warm them up on the bike. I decided to start with a fast spin, however I was closely monitoring my heart rate on the bike as my coach and I decided staying below a certain number was going to be important for me to be fresh on the run. The numbers for my heart rate were erratic, I was struggling in the beginning of the bike to try to control my heart rate and I just could never get it there. I made it to the first bike aid stop, and used the bathroom and grabbed a half banana for the road. That banana made the world of difference for me on the bike for my muscles at least. It took me over 3-1/2 hours to complete the bike course, strong winds, and poor road conditions were big factors. I felt okay getting off the bike but I knew that it was going to require every ounce of energy I had to complete the next stage of my race, a half marathon. It was hot and my body was tired already from over exerting my energy on the bike. I saw my family and teammates cheering me on during the run, I started running on the first loop trying to stay on top of my plan to walk/run every two minutes. Eventually the heat just got to me and I had to slow down and just take it easy if I wanted to finish completely. After the first loop I came back around and asked my coach what pace I needed to finish, she told me 16:00 minute per mile pace, my plan was to beat that number. I was making great pace every time I came around the loop - my sister, dad and teammates were cheering me on and motivating me saying “Keep it up you got this”! I would run for a little bit and then walk then run and then walk on repeat. I was having fun on the course and that’s what mattered the most. I finally finished the run coming down the finisher’s chute for a total of 7 Hours 59 Minutes and 44 Seconds! I completed my first ever Half Ironman!

In conclusion, of my path to complete a Full Ironman, my training is not anywhere near over. I have a tentative schedule for one or two more races before my season is over this year. Those will be running races. I decided to put my eggs all in one basket and try to see if I can get a slot at the Ironman World Championship Lottery program. I am not fast enough to qualify for any of the races, but I am fully capable of completing a Full Ironman. I still want redemption for my Half Ironman to complete it in less than seven hours, if I do not make it into Kona for the Lottery program. I am not fast enough to qualify for any of the races, but I am fully capable of completing a Full Ironman. I still want redemption for my Half Ironman to complete it in less than seven hours, if I do not make it into Kona for the Lottery program based on my story with Hypoparathyroidism, I will be doing another Half Ironman next season, or a different full distance race. I want to emphasize that I have gotten the clear by my doctor to do races. I have been training several years to be able to do these distances. My diet and training program that I manage with a private coach are set for me only. The most important thing about this journey is to have FUN!
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Cost to attend: Individual $95 – Supporting Member $85 – Lifetime Members $80
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HypoPARA Australia Kicks Off

By Tommy Ravlic

Patients and carers with an interest in hypoparathyroidism and related disorders have a new body to turn to in Australia. HypoPARA Australia has recently appointed a nine-member board with the mission to pursue improvements in the quality of life of patients and also better education for people dealing with those with the disorder.

The body’s chairman, Tom Ravlic, said the association’s main objective in its first year will be to enhance awareness and also ensure that it gives whatever support it can to patients seeking answers to questions related to what is a complex disorder.

The balance of the nine-member board is made up of Sharon Basswell, Sarah Jensen Znidarich, Richard Austin, Karen Marley, Nicole Rothery, Julia Roohan, Shelley Turner and Stacy Harben.

Amidst the key items on a work program for HypoPARA Australia are the development of patient resources for the website and background information for staff in emergency departments so that patients presenting themselves with hypoparathyroidism are better understood.

The association will also be looking for support from various government agencies in its quest to provide the best possible information to all patients with the disorder.

“HypoPARA Australia has been established to provide a voice to those that have not been heard either in the general community or the halls of government. Patients have for too long suffered isolation because it is a complicated disorder and their friends, family, medical practitioners and others have struggled to comprehend the magnitude of the disorder,” Mr Ravlic said.

“The board of HypoPARA Australia is made up of people that have had contact with the disorder in several different ways. My experience is unique on the board. I have had it since birth and it is currently being successfully managed.

Other board members have had surgery that has brought the disorder to them. We also have two carers on our board for whom the disorder has meant endless frustrations with less knowledgeable medical professionals.”

The board structure of HypoPARA Australia will consist initially of three board committees: a board executive committee, a stakeholder education and advocacy committee and also a fundraising and alliances committee.

“The committee structure will enable the board to function effectively and also create a situation where people can contribute to the association in a way that can be accommodated within their daily schedules. We must also bear in mind that each board member has their own challenges with the disorder. HypoPARA can bring forth unexpected surprises.”

The new association has already forged connections with international bodies.

“The board of HypoPARA Australia recognises the need to ensure we communicate with all our sister bodies across the globe. It is important that we speak with one voice on various issues. Awareness of the disorder can only increase over time if we as individual groups speak out in our home markets and also, where appropriate, engage with overseas counterparts in global initiatives”, said Mr Ravlic.

Australian patients will find that their questions will be answered fairly quickly by the board or the medical panel.

“We have a policy of rapid turnaround of queries. This will, of course, depend on the nature of the question. Our medical panel may be able to assist in some circumstances but in others general information will be provided,” Mr Ravlic said.

“Patients must also remember that we talk from our own experience and share our own stories. While this is useful it is no substitute for seeking the opinion of a qualified medical professional. I cannot stress this strongly enough. Hypoparathyroidism is a condition where patients can feel symptoms in different ways. There may also be other ailments that trigger symptoms that are like those that are common with hypoPARA. Patients cannot afford to second guess their medical condition and leave themselves in strife.”

Mr Ravlic said that over 43 years he had been under the care of good endocrinologists who have ensured his care was of the highest standard.

“I cannot speak more highly of the professionals that have cared for me. They have provided assistance whenever and wherever required. It is a privilege to have been their patient over a great many years. I owe them my quality of life today.”

Mr Ravlic said the association will be moving fast to develop e-mail newsletters and other communications for patients and carers.

“Our stakeholders have been neglected for too long. It is our intention to move as quickly as humanly possible to provide assistance to them. We have moved at record pace to get the association established. It is now time for us to deliver some benefit to our brothers and sisters with the same disorder.”

Patients wishing to contact the Australian body should contact Mr Ravlic either via his e-mail address ravlic.tom@gmail.com or phone at +61 407 408 000. Queries will then be forwarded to the appropriate board members or medical panel members for further comment and response.
In June, Claire Butchers and I travelled to Sacramento to represent Hypopara UK at the 8th International Conference on Hypoparathyroidism. We travelled out separately. Sacramento is not an easy destination from Europe, so to avoid hanging around airports while we waited to transfer to a local flight we met up at San Francisco airport and picked up a rental car to drive ourselves to the conference hotel.

More than 100 patients and carers attended the conference and it was an amazing experience to meet some of the people we know from Facebook and from the various online hypopara forums face to face.

I was impressed by the way the conference was organised and by the stellar line-up of clinical experts, many of whom I knew by reputation. This was cutting edge information, some of it not yet published, and the speakers took the issues faced by hypopara patients seriously, treating them to a great extent as partners rather than patients. As a former scientific and medical publisher I consider myself fairly well grounded in medical jargon, but I was having to work hard at times to keep up.

Claire and I were given a spot on the programme to talk about the work being done by Hypopara UK and Clare spoke movingly of her own personal journey – like many others we met at the conference, Clare has permanent hypopara after surgery for thyroid cancer.

My own story is a bit different. I have ‘been there, done that, didn’t quite get the t-shirt’. I had two surgeries for thyroid cancer which resulted in the loss of one parathyroid gland. Then, decades later, I developed primary hyperparathyroidism and needed another neck operation. I now have just two parathyroid glands but thanks to the combined skills of three endocrine surgeons and some good karma they both work. It is thanks to Jim Sanders and his team that I learned that Liz Glenister was starting up a UK hypopara group. I had joined Hypoparathyroidism Inc in the early days following my parathyroid surgery as I was looking for information about patient support for primary hyperparathyroidism, both to offer my help and to learn more about the condition myself. Jim placed an announcement from Liz in his newsletter and I contacted her offering to help with the UK group.

The conference gave us a lot of information to think about, and was also a great learning experience in how to organise a patient conference as we hope to run our own patient conference in the UK in the near future.

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Purchase your Awareness ribbon, lapel pin, wristband or t-shirt today. They are available for purchase by mail on the website – www.hypopara.org under HypoPARA Shop. So check out HypoPARA Shop today!

- $5.00/ea
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- $10.00/ea; purple w/lavender butterflies
- $10.00/ea; black with white
In 2004, when I was only 32, I had my thyroid removed as part of surgery to remove a goiter in my neck. At the time, I was a cake-baking wife, nursing assistant, and supermom to three children, ages 9, 7, and 4. I thought nothing could slow me down — I just didn’t have time!

A few hours after my surgery, I felt terrible — which was to be expected after the six-hour ordeal. That night in the hospital I didn’t sleep at all — I felt restless and anxious, like there was an active buzzing running through my whole body. I attributed it to normal surgery recovery at first. But the next morning when the symptoms were worse, my doctors told me my calcium levels were very low, which they said was normal after thyroid removal. They gave me antacid pills for calcium, and sent me home.

Just Keep Taking Antacids

I was glad to be home, but by the next morning, I knew something was really wrong. My whole body felt as if it were buzzing, and I began to experience numbness and tingling. My face felt so numb that the corners of my mouth were drooping down. My husband called the hospital where I had had surgery, and they advised me again that my symptoms were from low calcium and were totally normal. They gave me antacid pills for calcium, and sent me home.

My symptoms got even worse for the two weeks leading up to my follow-up visit with my surgeon, but I kept believing them — that it must be normal after thyroid surgery. I was taking the antacids like candy, and they were doing nothing. I could barely get off the couch to shower or eat, let alone take care of my three children or my house.

At my follow-up, the surgeon said my parathyroid glands might have been “stunned” during surgery and might not be functioning properly yet, which was causing my low calcium levels and symptoms. I was not even sure what parathyroid glands were, but again he assured me that this situation was normal and temporary.

My surgeon’s advice? Keep taking antacids.

My Parathyroid Glands Weren’t Working

I went home and saw no improvements for another two weeks. I had gone back to my job as an ICU nursing assistant, but could not focus on my work. I was having trouble concentrating, I had problems with my memory, and I was distracted. Finally, I had an appointment with an endocrinologist — a doctor who specializes in hormones. It was here, a full month after my surgery, that I first heard the word “hypoparathyroidism.”

Hyopoparathyroidism, I discovered, is when the body does not produce enough parathyroid hormone, or PTH — the hormone that regulates calcium and phosphorus levels in your blood. The doctor told me that sometimes low PTH is a result of damaged or missing parathyroid glands (tiny glands behind your thyroid). They can be damaged or removed during thyroid removal surgery, which was the case for me.

My endocrinologist explained that many of my symptoms were a result of hypoparathyroidism, and that this was a condition I would have to manage for the rest of my life. She put me on prescription calcium combined with vitamin D, which makes it easier to absorb calcium. She told me to take these every day, and sent me home with an order to come back once a year for blood work. Finally I had a diagnosis, but it turns out I still didn’t have the whole story — just a life sentence with hypoparathyroidism.

A Life Sentence: Take Calcium and Vitamin D

I went home and read everything I could about the condition online. I learned some things that my endocrinologist didn’t tell me, which was very upsetting. I read about research studies showing that high doses of calcium and active vitamin D can cause kidney damage. I learned that patients also need the right amount of phosphorus, as too much can lead to kidney damage and calcium deposits.
throughout the body. For patients who manage their hypoparathyroidism with long-term use of calcium and vitamin D, these imbalances can lead to calcium deposits in the brain, kidney stones, and heart problems.

From online message boards, I learned that despite taking calcium every day as directed by their doctors, many patients were unhappy and struggling, continuing to experience low-calcium symptoms. Many people said they were unable to participate fully in their work, family, and leisure activities as they had before they developed symptoms. I read their stories and despaired, afraid that the way I had been feeling for the past month was my permanent destiny. I thought, “Oh my goodness, what is going to happen to me?”

‘I Cannot Let This Happen to Me’

I was frightened and frustrated. I wondered why I was not told about the risk of hypoparathyroidism before or immediately after my surgery. I looked at the online messages of doom and gloom from other people with hypoparathyroidism and then at my three children and thought, “I cannot let this happen to me. I have to find a way to do better than this.”

Over the next few months, I learned to understand my body and my hypoparathyroidism better. Calcium levels can fluctuate regularly and are affected by things like stress, food, and illness. In a normal person, the parathyroid glands release as much calcium as you need to keep those levels stable. In someone like me who has no parathyroid hormone, you need to find another way to stabilize. I became good at sensing symptoms of low calcium when they came on and adjusting my calcium intake to keep my levels in balance and symptoms at bay.

It was very important to me that my intake to keep my levels in balance came on and adjusting my calcium levels stable. In someone like me who has no parathyroid hormone, you need to find another way to stabilize. I became good at sensing symptoms of low calcium when they came on and adjusting my calcium intake to keep my levels in balance and symptoms at bay.

In a funny way, hypoparathyroidism management can be very similar to managing diabetes — insulin levels fluctuate all the time and are influenced by different things. So no physician would ever expect a person with diabetes to take the exact same dose of insulin every day. And no physician would ever expect a patient to adjust their dose of insulin solely based on how they were feeling at that moment, without checking their blood levels first.

Yet that’s what people with hypoparathyroidism must do every day, because we have no way to check our calcium levels at home. All hypoparathyroidism patients have to learn to recognize their symptoms and be able to adjust calcium intake accordingly on their own. The alternative is to remain unable to function and be controlled by this condition and its symptoms, as the people in the online message boards I read had been.

Hypoparathyroidism Ever After

About four years after my surgery, I finally felt like I had control of my body again, and a good handle on managing my symptoms. As I started feeling better physically, I was inspired to feel better in all aspects of my life. I started eating healthier and walking, and eventually lost about 40 pounds. I progressed slowly from walking to running and eventually ran my first 5K race, and I continue to love running today.

I recently started a Facebook page for people with hypoparathyroidism who are, or would like to be, physically active. The page is called Athletes Beating Hypopara. My hope is to encourage and inspire other people living with hypoparathyroidism to get active, and to support those who already are. It’s important for other people to realize that living with hypoparathyroidism is only one small part of really living.

Jen Melanson is a 42-year-old mother of three active teenagers (one girl, two boys), and has been married for 20 years. She is an avid hiker, runner, and biker. She also enjoys baking and decorating cakes. She lives in Townsend, Mass.

This column was originally published on Everyday Health: Hypoparathyroidism Ever After:
The Hypoparathyroidism Association’s mission is working to improve lives touched by hypoparathyroidism, through awareness and support.

We envision a world where hypoparathyroidism is understood. Help us make this a possibility!