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It is Final!

The FDA has officially approved Natpara® for the treatment of hypoparathyroidism. January 23, 2015 will be a day hypoparathyroidism patient’s throughout the United States should circle on their calendar and celebrate every year with a calcium shake and a quick injection of PTH 1-84.

This day would not have been possible 21 years ago when I wrote the first newsletter about hypoparathyroidism. Nor would the decision on January 23, 2015 have been possible had it NOT been for the participation of many of our members around the world who participated in the many clinical trials, which were necessary to prove that PTH 1-84 was a viable and safe option for treating hypoparathyroidism. Many of them had to travel great distances several times during the clinical trials, often at their own expense to help make this day a reality for all of us.

They truly can be thought of as modern day pioneers, paving the way for the rest of us. Each of you are heroes, in my mind’s eye. To each one of you, thank you very much! You have made a difference in the lives of hypoparathyroidism patients everywhere. You have made a difference.

Kudos to everyone who stepped up to the plate.

Billy’s Fund

In November we inaugurated The Billy Sanders Memorial Research Fund for Hypoparathyroidism or “Billy’s Fund” for short. Again, a few of you stepped up to the plate, but we have a long ways to go before we reach our goal of $35,000 for seed money to issue grants for research.

We are close to reaching our Phase 1 goal of $10,000. There is a little over $8,500 in the fund now. We still have a ways to go but I know we can do it.

This year we are having asking anyone who wishes to donate items from their region, state, or hometown to help fill baskets that will be auctioned off to raise money for Billy’s Fund. The auction will take place at this year’s banquet.

Perhaps the next breakthrough for a medication for treating hypoparathyroidism is just around the corner, and they are anxiously waiting for research funds to complete the project?

9th International Conference on Hypoparathyroidism

Planning for the 9th International Conference on Hypoparathyroidism is well underway, and once again, we will have a very strong program waiting for you at the DoubleTree Inn in Minneapolis, Minnesota on June 4-6, 2015.

This year we are planning on some activities, which will not only help educate you about this “thing” which has invaded our lives, but we hope to equip you with tools, which will help make your day-to-day lives much easier to deal with.

Besides, we will have lots of fun as we learn. What better way is there to spend three days in June in Minnesota? To top it all off, the Mall of America is just a few miles from the hotel, and they offer a free shuttle every 30 minutes or so!

Manho’s Fund

We are beginning The Manho Edwards Memorial Conference Scholarship Fund or “Manho’s Fund” for short to help as many of those as possible go to the conference. Manho, who passed away from complications of hypoparathyroidism in 2010, was a strong supporter of the Association and the conferences. She epitomizes the struggle many of us have with hypoparathyroidism, and was an inspiration to all those fortunate enough to have known her. Background information on Manho’s Fund “is part of this newsletter. Your support could help many members to be able to attend this year’s conference as well as future conferences.

Research Papers on Hypoparathyroidism

Dr. Kim has written her latest review of published research articles about hypoparathyroidism. I know for me that they have helped me to understand the many complex issues about hypoparathyroidism. The current article ties the last two articles together and helps explain their relevancy to us today.

The articles help us understand hypoparathyroidism so we can be in a better position to work with the disorder, instead of fighting it, as many of us are prone to do.

Knowledge is power!

Patient Stories

We also have several patient stories in this newsletter, as well as some literary work by Nancy Watson. The stories help give me the power I need to deal with the many intricacies of hypoparathyroidism, while the literary additions inspire me.

What is your story? Do you have a story to tell which would help another hypoparathyroidism patient deal with some aspect of the disorder? Will your story help make someone else’s life a little easier, or inspire them? Have you written something (a poem, a six-word hypoparaism, a story or an article) which one of us needs to read today?

Send them to Nancy Watson at nancywatson@comcast.net

“Manho’s Fund” is part of this newsletter. Your support could help many members to be able to attend this year’s conference as well as future conferences.
Burden of Hypoparathyroidism: A Disconnect Between Patients and Providers?

By Kim L, MD

In the last several newsletters, I have had the privilege of reviewing some very important scientific articles related to the burden of symptoms reported by hypoparathyroidism (HPTH) patients, as well as the differences in perceptions of these symptoms between patients and surgeons. In this article, I will briefly review all three articles and attempt to tie them all together, from my perspective as both a physician/clinical researcher, and a post-surgical HPTH patient.

In the article by Bohrer T et al, “Permanent Postoperative Hypoparathyroidism – An Epidemiological Clinical Study Using a New Questionnaire Instrument,” published in 2003, the authors sought to identify, through survey methodology, which signs and symptoms and complications were seen in a random sample of 25 patients (out of 158) with permanent postoperative HPTH registered at their Endocrinology medical center until 2001. This was one of the first studies that systematically evaluated HPTH patients with thorough questionnaires and physical exams. The vast majority (92%) of patients were female, and over half (52%) had had thyroid cancer as the underlying diagnosis and reason for total thyroidectomy surgery.

Somatic symptoms experienced in a majority of patients included, in decreasing frequency: muscle pain (80%), joint pain (80%), cold sensation in hands and feet (72%), impairment of sexuality (72%), numbness/tingling [a.k.a. paresthesias] (68%), abdominal cramps (64%), sleeping disorders (64%), brittle nails (56%), and shortness of breath on exercise (52%). Bone pain was reported in 48% and a heaviness/weakness feeling in the musculature was reported in 44%, while cramps around the mouth and muscle cramping [a.k.a. tetany] were only reported in 16% each. Notably, complications such as cataracts, basal ganglia calcifications, osteoporosis and kidney stones were reported in patients who on average were of older age (over 40 years old), suggesting these are some of the longer-term complications of the disease. Symptoms that patients felt most burdensome were a heaviness/weakness feeling in the muscles, followed by joint and muscle pains, and lastly by paresthesias. Emotionally, patients frequently reported “sensitiveness” (44%), followed by “depressed and sad mood” (24%), inner unrest (20%) and fear (12%). Additionally, 44% of patients felt less intellectually efficient, which is often described as “brain fog.”

The majority of patients did NOT feel adequately helped by standard therapy (i.e., calcium supplements, activated vitamin D, etc.). Almost half (48%) had retired early (at average age of 48.8 years), and only 12% of patients younger than 40 years felt able to work regularly. Using two different overall scores for total symptoms and distress level, it was found that the actual level of PTH did not correlate significantly with either score, whereas level of calcium did.

This study described what many of us HPTH patients know all too well and live with on a daily basis – the burden of symptoms, both physical and emotional, fluctuate on a day-to-day, and sometimes even minute-to-minute, basis. Unfortunately, this study seemed to receive little attention in the U.S., most likely because of some limitations in the study design, including the fact that it was a random sample of only 25 patients from a single institution in a different country (Ukraine) than the U.S. Because Ukraine has a different culture from the U.S., and perceptions of illness may be strongly influenced by culture, it is difficult to extrapolate the findings of this study to the U.S. population of HPTH patients. However, it delineated for the first time, questionnaire items that could be used for future studies of HPTH, as the questionnaire was found to be easy and inexpensive to complete. This study confirmed the importance of calcium levels correlating with symptom and distress levels, as well as the fact that possible complications of HPTH should not be underestimated.

Fast-forward over a decade later, to the PARADOX study published in 2014 (Hadker N et al, Endocrine Practice 2014). It was the largest study to date of HPTH patients in the U.S. examining the clinical implications of the disease, including impact on multiple psychosocial aspects of a patient’s quality of life. One of the reasons that the PARADOX study was conducted was to see whether patient perceptions of HPTH were different in the U.S. than those reported by Bohrer et al previously. The PARADOX study surveyed only U.S. residents to minimize the impact of culture on symptoms...
reported. This study included 374 patients with HPTH, who completed an online approximately 30-minute questionnaire regarding 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. The majority (78%) were post-surgical HPTH patients, with 43% having undergone surgery for cancer. Most patients had seen multiple physicians to manage the condition. At diagnosis, the 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.

In PARADOX, HPTH patients reported experiencing an average of 16 physical, cognitive, and/or emotional symptoms, for an average of 13 hours per day. Postsurgical HPTH patients reported experiencing symptoms for a longer duration during the day than nonsurgical patients. The physical, cognitive, and emotional symptoms reported were quite similar to those reported in the study mentioned above by Bohrer T et al in 2003. The top physical symptoms reported were fatigue (82%), muscle pain/cramping (78%), paresthesias (76%), tetany (70%), joint or bone pain (67%), pain/heaviness/weakness in extremities (53%), and disturbance to bowel movements (48%). The top cognitive symptoms reported were brain fog/mental lethargy (72%), inability to focus/concentrate (65%), memory loss/forgetfulness (61.5%), and sleep disturbances (57%). The top emotional symptoms reported were anxiety/fear/inner unrest (59%), feeling sad/down/blue/depressed (53%), and emotional sensitiveness (47%). The most frequent comorbidities were heart arrhythmias (66%) and kidney stones (35.5%). A majority (79%) of patients reported hospital stays or emergency department (ED) visits, with an annualized rate of ED visits or hospital days for HPTH patients higher than the national average for the general population.

Perhaps most importantly, PARADOX shed light on the fact that for many HPTH patients, there is significant interference with overall quality of life. Comparing before vs. after HPTH diagnosis, there was a decline in full- or part-time employment status, and an increase in disability, retired, or unemployed status. For a vast majority (85%) of patients, HPTH prevented them from performing activities normally done around the house, and 72% strongly agreed that it is difficult for family and friends to understand their condition.

Taking both the studies by Bohrer T et al from 2003 and the PARADOX study from 2014, it is evident that HPTH is a serious, complicated condition that has, until now, been largely under-appreciated in terms of the multitude of symptoms and large negative impact on quality of life that it is associated with. There were some interesting differences in the results between the two studies. For example, intellectual deficiency was reported by 42% of Ukrainians, and brain fog by 72% of U.S. residents. It is unclear whether this quantitative difference in symptom reporting was due to Ukrainians’ accepting more variation in mental function before considering it abnormal, or if U.S. residents are more affected in brain function for some reason. It could be either or both, or true for some other reason, such as small sample size or cultural influences in the Ukrainian study. Nevertheless, the types of symptoms reported by the two studies were similar qualitatively, if not always quantitatively. From a personal standpoint as a HPTH patient, I can attest to the fact that fatigue and muscle weakness/heaviness, muscle and abdominal cramps, twitching, paresthesias, emotional swings, etc., and their impact on my quality of life have been highly significant.

In the study by Cho N et al in Endocrine Practice in 2014, it was shown that surgeons and patients disagree on the potential consequences from hypoparathyroidism. Utilizing a modified common standard form for assessing quality of life (QOL) called the Short Form (SF)-36, the study compared findings between three groups: (1) 102 “experienced endocrine surgeons,” (2) 200 preoperative controls, and (3) 340 post-operative patients with permanent HPTH. The preoperative controls were given a hypothetical scenario and asked to imagine that they were patients considering neck surgery, where the risk of HPTH was approximately 1-4%. The informed consent language provided to them was, “…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.” The subjects were then asked how they would expect to feel if they suffered from HPTH, using the SF-36 form. The surgeons were asked to think about patients for whom neck surgery caused HPTH, with questions asking them to rate these patients’ general health now; their health now as compared to before the surgery; interference with normal social activities and daily life.

This study found that both surgeons and preoperative control subjects 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. This trend was similar with regard to particular symptoms such as significant paresthesias, muscle cramping, and all dimensions of the SF-36 form. Patients with HPTH reported significantly lower QOL scores than preoperative controls; the largest difference was in the energy/fatigue dimension.

The upshot of this study is highly relevant to medical and surgical practice with regards to postsurgical HPTH. This study’s conclusions suggest that the standard informed consent language regarding the risks and symptoms of HPTH provided to preoperative neck surgery patients does not accurately reflect the real risks of living with the condition long-term. There is certainly the chance that the postsurgical risk of low calcium can be short-term (i.e., less than 6 months in duration). However, for those of us left with long-term HPTH (i.e., greater than 6 months in duration), the negative effects on QOL and burden of symptoms (as demonstrated in the other two studies discussed earlier) are clinically significant. The surgeons providing informed consent to their preoperative patients should be educated on the findings of the PARADOX study, and informed consent language should include the fact that risks of living with HPTH include fatigue, muscle weakness or difficulty exercising, cognitive, and emotional symptoms, as well as the paresthesias and intermittent muscle cramping, which may significantly impact QOL.

Many postsurgical HPTH patients, in particular, feel misunderstood and distrustful of the medical establishment. This is likely at least in part due to the disconnect between what was told to them preoperatively during the informed consent process, and how they actually feel if they did indeed suffer the complication of postsurgical permanent HPTH. To add insult to injury, many often feel misunderstood by their physician(s), due to the fact that until now, few studies have shed light on the full spectrum of symptoms and complications associated with HPTH. Hence, few physicians overall understand that many symptoms described by patients are, in fact, likely due to the HPTH itself.

So where do these three studies leave us? We are at an exciting and promising time, with Natpara (PTH 1-84) recently approved by the Food and Drug Administration (FDA) for the treatment of HPTH not controlled by standard therapy. However, this drug is still not a “cure,” and the best scenario for postsurgical patients is one where HPTH did not occur to begin with. Hopefully, with these studies’ results emphasizing the heavy negative burden of symptoms from HPTH, the “disconnect” between postsurgical HPTH patients’ experiences of living with the disorder compared to surgeons’ expectations will diminish. Surgeons performing these thyroid/neck operations will hopefully recognize the necessity of reducing the rates of this postsurgical complication. Just as with preventing recurrent laryngeal nerve injury (i.e., leading to problems with hoarseness from vocal cord damage), even more extreme care must be taken to identifying and preserving all four parathyroid glands and their blood supply. Better informed consent processes may even lead some thyroid/neck surgeries to be deferred, as the benefits may not be felt to override the risks in specific cases.

Beyond the postsurgical HPTH patients and surgeons’ practice changes, these studies hold promise for improving doctor-patient relationships across the board for HPTH patients. All too often on the HPTH support sites, I see comments taking aim at doctors for misunderstanding, poor care, etc. In my opinion, one of the reasons that most general practitioners and even general endocrinologists do not understand how to optimally care for HPTH patients is due to its rarity and lack of experience with multiple patients with the condition. The two survey studies reviewed here clearly delineate the wide spectrum of symptoms that the majority of HPTH patients experience. Admittedly, the major weakness of both the Ukrainian study and the PARADOX study is that there was not a control group (i.e., comparable group of subjects similar in age and sex, but without HPTH). From a purely scientific standpoint, this makes it very difficult to be sure how many of the symptoms were truly due to HPTH. Being a HPTH patient myself, I suspect the majority of the symptoms are due to the condition, or at the least, aggravated by hypoparathyroidism. However, other physicians are not as easily convinced because they do not see very many patients with HPTH. Hence, many of us HPTH patients, including myself, have had at least one care provider state that it is “doubtful” that the symptoms could be related to HPTH. Notwithstanding this, expert physicians who are involved in studying HPTH do acknowledge the complexity and burden of this disease, because they have experience with seeing more HPTH patients and also are familiar with the above studies. The more that all physicians and other care providers are educated on the findings of the PARADOX study, the more likely that HPTH patients will feel understood and “listened to” during their doctor visits.

Furthermore, these studies lay the groundwork for hopefully many future studies in HPTH, looking at outcomes not only regarding calcium/calcitriol doses and/or urinary calcium levels, but also QOL measures and nerve and muscle function meas-
ures. We eagerly await the results of QOL outcomes (as measured by the SF-36 form) in the phase III clinical trial of HPTH subjects before and after taking PTH 1-84 (i.e., Natpara). This trial did include a control group of HPTH subjects receiving placebo. Both the treatment and control groups’ symptoms should approximate the symptoms of the PARADOX study at baseline, but diverge with treatment if PTH 1-84 improved symptoms. In concept, if this is indeed shown, it would be “proof-of-principle” that HPTH is the culprit behind the negative QOL and burden of symptoms, if replacing the deficient hormone improves these outcomes. My hope for the future is that endocrinologists and others studying HPTH will expand their focus to include not only the bone and mineral aspects of the disease, but also the myriad other critical functions of PTH, especially from a neuromuscular and psychological standpoint. This may require collaborations with Neurologists and Psychiatrists, and perhaps even Physical Medicine specialists, in order to study optimal therapies for improving muscle and brain function in HPTH patients.

ACKNOWLEDGMENTS:
I would like to thank Dr. Bart Clarke, Dr. Kelly Liang, and Michele West, MPH, RN, for their helpful reviews of this article.

Calling All Would-Be Volunteers!

We need several people to help at this year’s conference in Minneapolis. This is open to all family members/caregivers!

In exchange for your help you will get a free t-shirt and a free one year Supporting Membership. Already a Supporting Member? We will extend your membership for another year!

For more information and to sign up, contact Jen Woodard at jenifer.woodard@yahoo.com.

[Note: We will make sure you will not miss out on any of the speakers or classes.]
The Food and Drug Administration (FDA) approved Natpara® for the treatment of hypoparathyroidism on January 23, 2015, which quickly became a cause to celebrate by hypoparathyroid patients in the United States. It was a long time in coming and certainly one of main goals of HypoPARAthyroidism Association for over twenty-one years.

Many of you have asked some valid questions concerning the impact of the FDA’s decision. I will try to answer some of the more frequently asked questions as I understand the information provided to me. This is not intended to official information from NPS Pharma or replace your doctor’s guidance.

**Will my doctor be able to prescribe Natpara® for my type of hypoparathyroidism?**

The FDA approved Natpara® for all forms of hypoparathyroidism with few restrictions, except for pseudo-hypoparathyroidism.

**Will I be able to get a prescription for Natpara®?**

NPS Pharma has set up a program called NPS Advantage to answer your questions and to help you with the steps you and your physician will need to take to get a prescription. To find out more information and to contact NPS Advantage go to their website [https://www.npsadvantage.com](https://www.npsadvantage.com) or you can call them at 855-TEAM NPS (855-832-6677).

**Will my doctor receive education on hypoparathyroidism and training on how to prescribe Natpara®?**

Natpara®, as far as we are aware, has not had problems with osteosarcoma. However, some rats in earlier PTH trials developed osteosarcoma. Let’s keep in mind the rats are bred to develop cancer and they were given toxic levels of PTH. You will not receive the levels that they received.

There are several hypoparathyroid patients in clinical trials who have been taking PTH 1-84 (which is Natpara®) for many years now without developing osteosarcoma. My best suggestion is to talk with your doctor about this risk and decide for yourself.

I have signed up with NPS Advantage and registered my physician so he and I will be able to obtain Natpara® as soon as it is available in Idaho. We will be able to move forward with confidence Natpara® is not only safe for me, but will be a more effective treatment for the disorder I have lived with for over 58 years. **I hope my kidneys and I will be able to do the happy dance.**
Tools that Help Make Living with HPTH a Little Easier

By Cindy Schriver

We all are intimately aware of the often-overwhelming issues that go along with a diagnosis of Hypoparathyroidism and the general lack of knowledge with some of the practitioners out there. You have to be your own health advocate, arriving at each appointment with all the information for a doctor to be able to get an accurate picture of the health issues that you are dealing with. From medications, both over the counter, vitamins and prescribed medications doctors need to have the complete picture of how your health is so they can help the best they are able.

I have HPTH, I have a daughter with Epilepsy and I have two other children so keeping track of medical issues can be a bit overwhelming to say the least. I have turned to technology. There is a new Web site/Application out called CareZone.com. CareZone can be accessed on your computer through the website or downloaded as an app to your smart phone or tablet. CareZone is a site that lets you enter your medication lists and when you take them, along with any issues you have had with the drug. It allows you to keep a journal where you can log the progression of symptoms and a place where you can even upload pictures to help explain your issues. Below is a picture of my profile.

I have all the contacts for my various pharmacies and my doctors right at my fingertips.

Another great feature of the site is place where you can create a to-do list. My number one to-do is to find a new Endocrinologist.
The photos and files section is great to keep copies of recent blood work or other medical tests as well as pictures of new symptoms. The medication that I take for arthritis pain caused me to break out in hives this month. I know that by the time I get to the doctor the hives will be long gone but I used my smart phone to capture the hives when they happened and stored them on this website so I can easily show the doctor when I see him.

The next section I would like to show you is where you list all your medications, the strengths and why you are taking the drug. Controlling any health issue with medications is a balancing act and we need to make sure we give our doctors a clear and complete picture of all the medications we take prescribed and over the counter and here you can list them all in one place. CareZone can be downloaded to your smart phone or tablet making it handy when the doctor asks for a current medicine list.

The last part of this amazing site I want to tell you about is the Journal page. You can keep a journal that chronicles what you are going through.

Personally, I am probably the worst patient ever. I have recently found myself without insurance and not able to afford the Calcitriol that we depend on as HPTH sufferers. I was managing okay at first but the symptoms of severe vitamin D deficiency began to really take their toll on my body and mind. I began to keep the journal of my symptoms so when I can get back on my medication this week and go to the doctor, thanks to a new insurance plan, I can show the doctor what I am dealing with and he can help me recover from my own stupidity.
I wish I would have known about CareZone when my husband was alive and battling cancer. During that time I learned then that we are our best advocates and the doctors are “Practicing” medicine. They are not fool proof and they do not know it all. It is up to us as patients and caregivers to make sure that we keep up with every aspect of our health and make sure that the doctor is aware of everything that we are going through.

My husband had liver cancer and I told the doctor that his liver was failing and they couldn’t see what I was seeing with his monthly doctors visits. So I began to take pictures of him daily so the doctor could see the change in the color of his eyes. When I showed the doctor the pictures the next week he ordered tests that confirmed my suspicions and they were able to help ease his pain quicker.

As a patient with a rare disease like HPTH that can effect nearly every part of your body it is vital to be on top of every symptom or pain so that doctors can stop something small before it gets big or manage a new issue better.

CareZone will help you manage all those medication and symptoms and you will be able to present your doctor with all the tools he or she needs to provide the best care.

Knowledge is power when treating and living with rare diseases and thanks to technology it just got a little easier to organize all that knowledge.

SHOW YOUR SUPPORT!

Purchase your Awareness ribbon, lapel pin, and wristband today. They are available for purchase online on the website - www.hypopara.org under HypoPARA Awareness Products.

It is available for purchase along with lapel pin and wristband. The prices are kept low to allow for all to purchase them - the proceeds will go to support the Association.

$5.00/ea $2.00/ea $5.00/ea
It only took 43 years

It only took 43 years for me to speak to somebody that has the same disorder with which I was born. That is – by any stretch of the imagination – a rather long time.

In fact, the conversation took place on my 43rd birthday. You see, I have never until recently been seen or spoken to another patient with hypoparathyroidism.

I had spoken to my parents who were my primary carers. Endocrinologists and doctors were the other people with whom I dealt.

But at no point did I have this conversation with somebody that felt the same way, knew the disorder intimately and was able to have true empathy for its effects.

The ability to have the conversation with somebody who knows what the condition is and how it affects a person was a godsend, a moment that will remain unforgettable.

Up to that point I felt completely isolated and at times prone to a touch of depression.

Why?

You would think that being surrounded by loving family and friends that it would be easy to handle having hypopara and that familial support would lend itself to you feeling better about your chances of fighting the disorder.

That is true to an extent. Familial support is important, but nobody in a family can truly share the feeling of the disorder with you unless they have experienced it themselves.

No member of my family has hypopara, you see. I have had it since birth and have grown up with the routine of blood tests, visits to specialists, periodic adjustments of doses of medication and at times panic attacks about symptoms that were not hypopara-related.

I am what I refer to as ‘limited edition’ in my family and the disorder has very much shaped the lifestyle of the family during my childhood. I was one of only two infants diagnosed with hypopara at the Royal Children’s Hospital in Melbourne, Australia in 1971. What readers must remember is that around that time any treatment of infants with the condition was experimental. Doctors were only beginning to get their head around what the treatment should be for infants in order to ensure the disorder is reined in and the infant can be stabilised.

My parents went through hell. Both were learning English at the time and struggling to come to terms with the fact their newborn son had something rather odd. The medics did all sorts of tests to attempt to work out what was wrong with me at that time. I fell into at least three comas during the attempts by doctors to treat me and stabilise the condition. My parents were at one stage told that the best prognosis for me was that I would be retarded and may need to be placed in a home. So much for the medical fraternity’s knowledge of the implications of hypopara for infants at that time.

It goes without saying that I have not seen the inside of a home and my career has been nothing short of remarkable given what some individuals had forecast would be the case with me.

There were activities that were out of the question for me because of the delights of fatigue and the need to rest up as a youngster. Sport could only really be tolerated in short bursts while other children were able to do more in the sporting department. I spent my time behind the covers of books, writing stories, learning music and writing songs.

Music is a passion of mine and that was in part due to the fact my parents brought me up to learn the organ and piano. Quite apart from the cultural benefits playing these instruments actually helped strengthen the muscles in my hands and as such over the years there was less of a chance of tremors making too much of a hassle. My fingers are as strong at this time as they were when I first began to play the piano and organ.

There were therapeutic benefits to music from the point of view of exercise. It also taught me a means to deal with the isolation this disorder was going to make me reflect on for much of my life.

Nobody understood what the disorder meant. Nobody really understood why I got sick or lost my voice as a teen. It marks you as different and as such schoolyard taunting for no good reason becomes the norm.

While I have eye trouble that can be dealt with individually and partial hearing loss both of these were in some form because my main hassle health wise was hypopara. All of these things are interlinked, which is why it infuriates me still to this day to hear that people are being sent to individual specialists and not being treated holistically as a person with a disorder that has many different ways in which is can affect the patient.

Do I get symptoms of hypopara still even though I have had it since day one? The answer is most definitely. Forget a dose of calcitriol. I will feel that by midday. Fail to take the
Calcium dose by mistake the night before and I feel a bit of tingling about the face. All of these things can still occur despite me being relatively under control. I have not had to go and get an infusion of calcium at an emergency department of a hospital in years. You cannot, however, predict what changes might occur at some point that create the need to go and get a calcium boost of that nature.

I generally find the disorder does not limit me in achieving things that I want to make happen. HypoPARA Australia is moving rapidly and shaping up as a body that will be able to advocate on behalf of people with the condition. It has moved quickly simply because I have wanted to see us make quick progress.

I am also involved in managing a singer-songwriter by the name of Emma Sidney. Feel free to visit her web site. Music is something in which I am thoroughly interested and managing Emma has allowed me to indulge that more than I otherwise might.

Life for the current time is full and has its challenges. I have to some degree been successful in not allowing the disorder to completely dominate my life but I concede that things can be unpredictable. That is why I am dead keen to pack as much in as I can while the going is relatively good. Who knows what will happen further down the track!

Manho Edwards Memorial Conference Scholarship Fund

By James Sanders

One of the things, which makes the work we do memorial, is the inspiration we receive from our members, many of whom are truly heroes and a source of inspiration to each of us. Manho Chou Edwards was just such a person, and one who passed away from complications from hypoparathyroidism on February 18, 2010.

Manho was a Chinese émigré who lived in Washington D.C. for eight years, preceding her death in 2010. She had long suffered from the effects of thyroid surgery, which ultimately lead to her death from renal failure.

Manho was born on April 4, 1934 in Hangzhou, China. She was the eldest of six children. Her father was a Chinese Air Force officer and regional magistrate serving in the Kuomintang government under Chiang Kai-shek.

During the war with Japan, which started in 1937, the family moved around China, with stints in Yunnan, Chunching, and Chengdu. Manho vividly remembered the severity of the Japanese bombing even in countryside. She recorded in her private memoirs how she and her siblings would blow out their candles and hide under their beds when the bombs dropped.

She also remembered American relief planes dropping supplies, including Kim Powdered Milk and Gerber’s Baby Cookies. The care packages also contained small black scissors.

She kept a pair as a treasured memento of those times.

Manho’s family in China had many prominent members, including her uncle, the major poet and essayist Zhu Ziqing. While most of the family were fleeing the Communist takeover in 1949, Mao Zedong praised her uncle in a famous anti-imperialist speech entitled “Farewell, Leighton Stuart!” referring to the last US Ambassador to the nationalist Nanjing government. Another maternal uncle was Zhu Wuhua, China’s first Harvard PhD in physics and president of Shanghai Jiaotong University, often called “China’s Caltech.”

The family settled in Taiwan. It was there in 1959 that Manho met her future husband, Robert Randle, a young US Navy officer from Alabama, who had studied Mandarin. The couple married in 1961. The Navy threatened him with early discharge from the Navy for marrying “an aborigine.”

The couple moved to the United States in 1961, first to Massachusetts, and then to the New York area, where he was a professor of Chinese Law at Columbia University.

Manho was a person of many talents and active hobbies, including playing the cello, cooking, and letter writing. She received a bachelor’s degree in General Studies in 1981 from Columbia University.

She suffered from hypoparathyroidism, because of surgery on her thyroid gland, and was an advocate for fellow victims of the disorder.

Survivors include her husband, Robert Randle Edwards; her children, Lee Edwards of Beijing, China; Sue Edwards of Washington, D.C.; and Jon Edwards of London, England.

Manho was a strong supporter of the HypopARathyroidism Association and attended several of our conferences in Rockville, Maryland.

I personally cannot think of any greater tribute to Manho Chou Edwards than to name the Hypoparathyroidism Memorial Conference Scholarship Fund after her in honor, and in memory of the life she lead. All donations to the Manho Edwards Memorial Conference Scholarship Fund will be able to be part of these all important conferences. We ask you to be generous to this end, in memory of Manho Edwards and to those patients who would not be able attend.
HypoPARA Reflections: Living with Hypoparathyroidism

By Nancy Watson

The HypoPARA-Post would like to add a new section to the newsletter. Over the years we have welcomed and enjoyed the many stories of our members. We think that many of you may also have much to share on his or her story of hypoparathyroidism, but in a different way. There are other creative or athletic outlets that we would like to showcase beyond the traditional story. Hypopara Reflections is asking you to show or tell us what having hypoparathyroidism means to you, or show us what you can do despite hypoparathyroidism.

We would welcome any form of expression we can show on the printed page.

Perhaps you could send us a photo of your interpretation of this condition in artwork, photography, crafts, textiles, woodworking, or anything your creative minds can imagine. Write some words of wisdom or some poetry. If you dance, do film, or are an athlete and have a video then we could put a website, Face Book, YouTube, or other e-address where it could be viewed. If you wish or need to add a short explanation of what you sent to go with the photo or writing, by all means do so.

We sincerely hope you won’t let Hypoparathyroidism steal your creative or athletic side and that many of you will share your products or achievements with us. You can email your contributions to: jsanders@hypopara.org. We will print a few of these “Reflections” each issue in the Hypopara Post. Help us show others what hypoparathyroidism means to you.

To get this started I will share what I like to do. Although I was a mathematics major in college I have always loved writing poems – silly limericks, serious matter, and plain ole rhyming verse. No matter how bad my form, it relaxes me.

This is my interpretation of the Para-

State & Country Basket Auction

Here’s a little friendly geographic competition of States and Countries to help support the Billy Sanders Memorial Research Fund.

We invite each you to help fill your State (or Country’s) basket for the Live Auction to be held during the Banquet on Friday night. We ask you provide something from your home State/Country, or from wherever you call home. Make your Hometown proud, celebrate your region’s gifts, and help raise needed money for Hypopara Research! No donation is too big or too small.

All proceeds will go to support the newly-named Billy Sanders Memorial Research Fund, named in honor of Billy, an older brother of James Sanders, founder and president, who died as a baby as a result hypoparathyroid complications.

If you have any questions or would like to send your donations early, please contact Dana Crumpton at dcrumpton66@gmail.com. See you at the conference!
PARADOX PEOPLE
(By Nancy Watson)

I’m a hypopara person living on this big round ball.
Many things can define me; you just don’t know them all.
Would you like to take the time to read and learn a fact or two?
About what the Paradox Report found hypoparas may go through.

Our bodies, once our temples, used to be our pride.
We knew what they were telling us, they were on our side.
But, let that little parathyroid not do its earthly deeds,
And suddenly our body doesn’t have the calcium it needs.

Now to the outside world we all may look just fine,
But our inside world has certainly lost its vigor and its shine.
At every turn anxiety now rears its ugly head,
While nearby ole depression lurks and keeps us in our bed.

And then there is the matter of a memory shot to hell,
An inability to concentrate or even sleep very well.
We often forget names and places, and words just won’t come out,
Tired, frustrated, and flustered, our sanity we begin to doubt.

Then nothing ever feels right - Feeling hot, feeling cold,
Feeling fatigue and sadness, and feeling downright old.
Families suffer, jobs suffer, and the joy in life is gone.
Yet reality calls us loudly, and somehow we carry on.

We often get a tingle here, or we get a numbness there.
It usually means low calcium and gives us quite a scare.
Will it lead to tetany, with its muscle cramping pain?
Or will it simply go away, only to return again.

Muscle cramps and weakness follow us everywhere,
It makes it hard to do our tasks, or live life without a care.
So, even if our joints ache, even with deep bone pain,
We often suffer in silence, misery our bane.

Worry for the future is so hard to keep at bay.
Will calcifications or kidney stones suddenly rule our day?
Or maybe renal failure, bone fractures or a bad heart?
All are possibilities; all play their little part.

Overall we’re just fatigued, no energy to spare,
Socialization, intimacy – often we just don’t care.
So it may look on the outside like everything is good
How Do You Educate the Medical Community About Your Disease When You Feel Like Crap?

By Dana Wieland

My Hypoparathyroidism (HPTH) is caused by a genetic defect since birth. I was born with DiGeorge Syndrome, a congenital defect involving a deletion of the 22nd chromosome (22q11.2). Due to the type of heart defect I had, the doctors suspected DiGeorge Syndrome. This syndrome causes parathyroid glands and the thymus to be missing or undeveloped. Because of exploration done during an open-heart surgery when I was three days old, my parents were aware that I had these issues.

I was a little over a year old when I experienced my first tetany episode. Hypoparathyroidism has been managed since then been managed by endocrinologists by adjusting my medications, including calcium supplements, based on lab results. I have been the topic of discussion by many doctors and medical students. My rare heart defect alone provides excitement in the clinical setting when the opportunity presents itself. Medical personnel have discussed my medical case all over the country. Educating medical staff is not anything new to me.

Are you able to relate to this scenario? You have been experiencing episodes of tetany, and cannot wait to see the endocrinologist so you might start feeling better. You finally make it to your appointment, but instead of the doctor, they send in a medical student. You are in the middle of a tetany, your hands are cramping up, everything is falling asleep, and your anxiety is high because you feel awful. The medical student asks questions after question, and does a precursory exam. The medical student leaves. You sit in that unfriendly exam room for what seems like hours (and maybe it is). Finally, the doctor comes back in but with the medical student. The doctor shows the medical student how to assess for tetany, and then has the medical student do the assessment. By now, you cannot stop your muscle spasms, and the doctor has not done anything to be of any help.

How do we advocate for ourselves in the midst of feeling ill and run down? How might we teach others with the limited amount of energy that we do have? I find it important to educate the medical community and public alike, because you never know whose life you might change. However, this feels like a monumental task when you feel ill and have no energy to keep answering questions.

I will be providing some things I have learned along the way including a program that might be a good resource. When you feel too ill to communicate to more than one person, you can always refuse the medical student. If the doctor is pressuring the medical student to have experience, you can ask that the doctor do the exam while the medical student is in the room. If the doctor is not willing to comply, refuse to see the medical student until you feel well enough to answer their many questions.

A notebook or journal might be helpful where you keep notes of key symptoms, doctor visits, vital signs, important lab results, lab renewals, prescription renewals, brief discussions, and questions you want to ask and the answers to those questions. This notebook helps tremendously when I am feeling ill and cannot remember everything all at once. It is a great resource for the doctors. Sometimes I just hand them the book to look through, because it is easier for them to browse then me to explain everything.

Provide your medical team with easy to remember websites with information they can look up on your rare health issues. Medical staff are willing to look up your issues when they have a moment. Finding websites that have everything in a concise but easy to read format, is helpful for them. While they may not know exactly how the condition affects you, it gives them a general idea of the kind of issues you might be experiencing.

Many patients are not aware that medical school programs are looking for patient volunteers, especially those with rare diseases. I recently joined a program through my local medical school, called “Longitudinal Patient-Centered Experience” (LPCE) program. “We know that much of what doctors do involves chronic illness, and we want our beginning medical students to have a long-term experience in working with people with chronic health problems.” (Kimberly Lyth, director of Michigan State University LPCE program).

Students are assigned to meet with a person and their family several times throughout the year. They can meet you at any place you designate, whether it is in your house, a coffee shop, the park, etc. If you are not having a good day, they can reschedule, as long as they give themselves
enough time to get the assignments done that correlate with their coursework.

LPCE assignment topics:
- Meeting the patient, reflecting on competency and compassion
- Health Beliefs, reflecting on respect for others
- Meet the Family, reflecting on honesty
- Stress & Coping/Genogram, reflecting on social responsibility and professional responsibility
- Advanced Directives, reflecting on advanced directives and end-of-life decisions
- Health Care Policy/Completing LPCE, reflect on the effect of health care policy on their volunteer’s medical care and health

This program is a yearlong program from January to November, with six scheduled visits. This is my first time participating on my own in this program. A number of years ago, a friend asked me to meet her first year medical students that were involved in a similar program through a different university. The Hypoparathyroidism Association newsletter staff has asked if I will consider writing an article following the completion of the program. The medical schools and hospitals are also interested in real life patients for their simulation scenarios. If any of you are interested in similar programs, I encourage you to contact your closest medical school for more information.

Dana Wieland, is 34 yrs old, born with DiGeorge Syndrome, Truncus Arteriosus, Absent Thymus, and Absent Parathyroid glands. She comes from a background whose mother worked as a tech in a medical lab before Dana’s oldest sibling was born. Her mother has a background in chemistry and biology. Her father is a mechanical engineer. Dana’s mother trained her well in how to communicate with her medical team, and advocate for herself. Dana uses this training to research and educate herself to be as healthy as possible.

A Parathyroid Dream

(By Nancy Watson)

As my life lengthens on and stretches closer to its end, I think of the things I want to do and the messages to send.

My wants are quite simple, at least for someone like me, What others may take for granted, for me may never be, I want to walk in the wind with a spine straight as a tree, Carried along on two strong legs to let me walk far and free.

I want to dance and twirl, for my feet to come alive, To parade to church in patent shoes like I did when I was five.

To once again have my body free of aches and muscle pains, Free of wheelchairs, free of walkers, free of walking canes.

Another dream is clarity, a clearness of thought so sane, To see a face or hear a name and know it’s caught in your brain.

Free of boxes filled with pills and all the regimen that entails, To wake up with a mind that’s free - of worry, anxiety, and fails.

Once more I want to feel a body that is happy and full of energy, A body ruled by God or me, but not the almighty C.
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I call myself a calcium junkie. Every now and then a person will look at me confused and ask for an explanation. I usually explain hypoparathyroidism in a few sentences and then go into this story:

“Once when I was in the hospital I was afraid that the nurses would not bring my calcium fast enough. When I need my calcium, I NEED my calcium. I called my husband in the middle of the night, panicked that the nurse was not understanding hypoparathyroidism. My husband snuck a bottle of calcium into my hospital room. I hid them in MY SHOE. I needed the security of knowing that I could get my calcium at a split second if needed. I hid CALCIUM in my shoe so I would know I could get to it. That night was my first clue that I may have issues with needing calcium around me. And trust me I stash them EVERYWHERE. So this is why I call myself a calcium junkie.”

On a serious note, I know I need more then calcium to survive hypoparathyroidism but calcium seems to be the big thing I obsess about. The day I first called myself a junky was the day I knew I would survive this horrible disease. I was a little over four years post TT surgery and hypoparathyroidism. The first six months I was sick but not depressed because I knew within six months my para’s would ‘wake up’. At six months and one day I spiraled into a deep depression that lasted until four years later, 4 hospital stays (averaging nine days), a bucket of tears, and a million fist shakes at God long. During those depressed years I passed numerous kidney stones, was placed on a few different diets, broke a few bones, went through a few doctors and feared I had lost who I was at the core. In a nut shell I had lost all hope!

The day I decided that I could sit and have a pity party for one for the rest of my life OR I could embrace my new normal and find a way to live was they day I found my hope again. Just because I made a decision to live again does not mean my illness got better and life was great again. Actually, my health became worse as my kidneys began to fail. I just decided to laugh at the things I wanted to cry at and not let one change in my life change who I was. I was a happy, funny, easy going mom before the surgery.

I continue to live with constant fatigue, bone pain, and tingling throughout my body. My symptoms get worse when my activity level increases, so instead of being an active mom of three, I am a spectator in my family’s life. But I am the best spectator I can be, I clap the loudest, cheer the most obnoxiously, and high five better then anyone else around. I learned that being with your family is just as good as doing things with your family. I am lucky my family knows I am sick and is happy for the good time I can spend with them but never makes me feel guilty for the days I cannot get out of bed. I am way harder on myself in the guilty area then my family is.

While battling this illness I completed undergrad school and grad school becoming a Doctor of Health Science, watched two kids graduate high school, one kid graduate college, taught myself to knit, and learned to sit still and just be. I used to run, play ball in the yard with my kids, rough house with my kids, and spend a ton of time outside doing things. Now I read, swim, nap, knit, watch my kids play, and sit in the shade. I have had to change how I interact with my family but that does not change who I am to my family.

Today I am a few weeks shy of ten years with hypoparathyroidism and I can honestly say, I am a better person because of hypoparathyroidism. That is something I never would have dreamed of saying five years ago. Perspective is a wonderful thing!
The mission on the HypoPARAthyroidism Association is to improve the lives of those touched by hypoparathyroidism through awareness and support.

To grow,
To cope,
To learn,
To hope –
towards a cure.

James Sanders