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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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Jim’s Corner

It has been a roller coaster ride for me since we published the last newsletter just three months ago. It is amazing how time flies, especially when you are having fun.

We are planning for the 10th International Conference on Hypoparathyroidism and it is well underway. The conference, which will be held on June 2-4, 2016, at the Hyatt Regency Jacksonville Riverfront, in Jacksonville, Florida. The City of Jacksonville and the Hyatt Regency Hotel are going all out to make you feel welcome.

The Hyatt Regency Hotel has offered us an excellent room rate for the conference, but the discounts will not be available forever, so make your reservations now for what could be a life-changing event for you and your family.

We will post specific details and information on our web site as quickly as we can. Check it often so you do not miss anything.

Since the long awaited news about Natpara, one of my primary concerns, and yours I presume, was “Can I afford it?” I found out I had other obstacles to overcome as well.

My primary care physician (PCP), my endocrinologist, and my nephrologist all felt I would not be a candidate for Natpara, because they felt I was “well managed”. Granted my calcium level has been within the “normal” limits for serum calcium, but I wondered what exactly is “normal” and what is “well managed”? These were legitimate questions, especially since I have already had cataract surgery on both of my eyes, have calcium deposits in the basil ganglia, have retired from my job because of brain fog, and I have been diagnosed with stage 3 kidney failure.

Luckily my former PCP was willing and helped complete the paperwork necessary for me to get Natpara to treat hypoparathyroidism. The one question that remained was the final cost to me.

The first place I started was One Path at Shire. Their toll free phone number is 1-866-888-0660. My counselor at One Path enrolled me in their program and explained how the process would work with them. In addition, she gave me the names of two resources, which would be able to help with the copays, which were high with my Medicare Part D Insurance, $2816 for the first month, and $403.60 per month afterwards. That was far better than the full price of over $8000 a month, but still more than I could afford.

I then went to the resources that Shire recommended and it turned out I qualified for both of their programs. Both of them told me they would cover ALL of the copays for Natpara. Natpara would not cost me anything, which I could certainly afford.

I did my happy dance!

I hope to receive my first injection of Natpara by December 2015. It will be the first time I have had PTH since the early 1990’s when I was in a research protocol at the NIH.

You should contact One Path yourself if you are at all interested in getting on Natpara. Every patient is different.

I am still doing my happy dance!

From what we have able to discern, several of our members are now using Natpara, and the overall results are favorable. Some of their patient’s stories are included in this newsletter. One thing that is clear to me is that we now have FDA approved hormone replacement therapy for the treatment of hypoparathyroidism.

The journey took over twenty years to complete, and it appears to have been well worth it. I hope you will call One Path, and try Natpara. It might make a huge difference in your quality of life.

We added two new members to the Board of Directors: Dana Crumpton, Wisconsin, and Deb Murphy, California. Look for their bios later in this newsletter.

We are excited about being able to work with them as the HypoPARAthyroidism Association moves forward into the future. Dana has been working hard to make the 10th International Conference on Hypoparathyroidism the best conference ever. Deb is already working on things which will ultimately benefit each of you.

Jim’s Corner
GET TO KNOW OUR NEWEST BOARD MEMBERS

DANA CRUMPTON, CHAIR OF THE BOARD

Hello, my name is Dana Crumpton and I live in Madison, Wisconsin, with my Partner Ron and we have a 14 year old daughter. We have 4 cats and 1 rabbit and I love winter as long as there is snow on the ground.

I was diagnosed with Familial Hypoparathyroidism in 1974 at the age of eight, my grandfather was in the hospital being treated for a heart attack and they realized his calcium level was extremely low. He was the first in my family diagnosed with hypoparathyroidism, so the endocrinologist tested the whole family. The results were interesting to say the least; it skipped to every other person. Three out of five of his children had it. One interesting point is he had twin daughters: one had it, one didn’t. My father passed it to me, yet my younger brother did not have it.

In December 2014, with the help of Dr. Mannstadt at Massachusetts General and his genetic study, I finally found out what caused my hypopara. I have the G11 gene mutation; this particular gene tells the parathyroid when to release calcium. My gene doesn’t work so no calcium gets released.

I enjoy traveling, working with the hotels in planning our conferences, and my hobby is LEGO. In 2016 I turn the big 50 and in August I will be riding in the Wisconsin AIDS Ride, a 300 mile 4 day bike ride.

My professional background includes over twenty years in the Hotel industry and for the past ten years I have worked in the Insurance industry in the claims division. In 2014 I received my Bachelors Degree in Healthcare Management. I am excited to be a member of the Board of Directors of the HypoPARathyroidism Association. One goal is to use my hotel background to help with planning the yearly conference and make the conference not only informative for the patient but also make it a family vacation. For most patients the conference is their only vacation so I want to make the best of their trip. I also want to help make the insurance issue less painful. Over the past 41 years I have learned the ins and outs on how to deal with the insurance companies in regards to hypopara.

DEB MURPHY, BOARD MEMBER

My name is Deborah Jo Murphy and I have been hypoparathyroid for almost 22 years due to thyroid cancer. The parathyrals were encapsulated in my thyroid and could not be saved, they said. With my husband in the Navy, I moved every 3 years for a good part of my life. Because of the constant moving, I have had to be proactive in regards to being hypopara. Having an assortment of endocrinologists, I have had a variety of treatments. I am currently on the HPTH study at NIH under the care of Dr. Rachel Gafni.

This trial is soon to end and I will be adjusting back to calcium and calcitriol before being able to try Natpara. My life is coming back to me due to the use of PTH-34, so am excited to see what Natpara will do.

I am the Athletic Secretary at Lemoore High School, in Lemoore, California. I am married to Glenn Murphy and have 3 wonderful daughters, Sarah, Amanda, and Emily. I also am grandmother to 3 wonderful grandchildren.

I have been an ombudsman for the Navy on two tours for a total of 6 years. I have also been involved in Relay for life for the last 9 years, Event Chair for 2 of those, and Chair of the Survivor Committee for 4. I am a member of the Lemoore Presbyterian Church Choir. (Which is a feat as I only have one working vocal cord!) And I am involved in all my daughters schools and band and FFA and on and on.

One of my philosophies of life is from 2 Kings 7:3 “Why sit we here until we die?” I will never accomplish anything by sitting and complaining about how things are, I need to see where things will go, and push myself to be better than I am now. I want to make a difference. Another of my philosophies has evolved due to working in athletics and that is, “Not all team players have numbers on their jersey’s”. That is me, a team player with no number, just spirit!!
FINALLY, RELIEF!

By Chari Gauntt

Scary, unsure, hopeful.... These are all words that describe where my mind was at, just a month ago... Just one short month ago was when I was about to make the transition from Forteo to Natpara. In a nutshell, I was changing from one type of parathyroid hormone to another. Going from injecting Forteo (pth 1-34) NINE times a day, on top of oral medications.... To start, injecting only ONE Natpara injection a day on top of keeping my oral medications the same. Could this be true? Could my body really handle needing NINE (20mcg) injections of Forteo a day to only ONE (100mcg) injection a day (plus orals)? Who knows? I was scared, I was extremely unsure of whether it was going to work or not, but I was trying to stay hopeful and optimistic. I had high hopes, but as we all know (those of us who struggle with the unknowns of hypoparathyroidism), there is no perfect answer. What is right for one person may not be right for the next. I, myself, am on about eight times MORE pth than the average hypopara patient, yet I STILL bottom out and have calcium crashes that land me in the Emergency Room with STAT IV's about once or twice a month.

Well, it has been one month since I escorted the amazing NPS Advantage Nurse out of my home and closed the door behind her, after she showed and demonstrated how to mix and inject my Natpara, for the first time. Of course, subcutaneous injections are not, at all, new to me, but changing my daily regimen and routine was the part that I terrified me.

I was going to have to do something that I don't like to do, and that is "to put all of my eggs in one basket" and rely fully on Natpara and hope that the additional 50 amino acids (going from 1-34 to 1-84) will be the missing link and be the piece to the puzzle that my body needs, to feel and be complete.

Now, after one month of using Natpara (100mcg, once a day), in addition to keeping my oral medication routine the same (calcium citrate, calcitriol, magnesium and vitamin D), I can proudly report that I am doing GREAT. Before Natpara, I would wake up partially symptomatic every single morning of my life, with almost no exceptions. Whereas, I did my first Natpara injection on a Thursday morning, and for the first time, in a long time, I actually woke up that Friday morning symptom-free. It was such an amazing feeling. After living with one of the most severe cases of hypoparathyroidism documented... Could this be true? The "magic bullet" that we have been waiting for since I was diagnosed idiopathic hypoparathyroidism 24 years ago, at age 7.... Is it finally here? Is Natpara that magic bullet? Well, I am not a doctor, nor an expert, nor do I expect this particular Natpara dose to be the complete answer and solve all of my issues and crashes.... But I'll tell you what I am....

I am... hopeful.

I am... optimistic.

I am... better than I was in the days before Natpara.

And, most importantly, I am NOT giving up. Not on my self, my treatment, my options, or my life.

So far, Natpara has allowed me to feel the best that I have felt in many years.... Is it the do-all and end-all and will I never have to worry about my levels, calcium crashes and symptoms ever again? Of course not.

But for now, I am extremely happy that I made the treatment transitions as the research and treatment options became available. From only oral medications from age 7 to 23, to IV treatments every other day when the orals alone weren't enough, to entering the clinical trial at NIH and started injecting pth 1-34 until the trial ended it's compassion basis program after 5 years, to then transitioning to Forteo that I was using off-label nine times a day, and now, finally, at the age of 31... After 24 years of fighting and waiting for the FDA approval of commercial pth 1-84 (Natpara) for use in the treatment of hypoparathyroidism... I am now, finally being treated with the most current and up-to-date treatment there is, for an extremely rare and severe case of hypoparathyroidism.

So, my journey continues... I like to remain optimistic and stay positive through all of my ups and downs, and most importantly, never give up. My mother has told me for years... just like Dory told Nemo’s father, in the movie, Finding Nemo, "Just keep swimming..." Mom, I will. My father has always told me, "Looking back through history, the BEST day to be going through such a big ordeal like hypopara, is TODAY". Dad, you're right. Personally, I like to believe that, it is no coincidence that our windshields are so much larger than our rear-view mirrors... It's simply because what's in front of us, is SO much bigger and brighter, than the past we left behind.
THE 16TH BIRTHDAY SURPRISE

By Landan and Eric W

February 2011 was an eventful month for our family. We live in California in the heart of the Central San Joaquin Valley. Our oldest son’s sixteenth birthday was coming up and we were both excited and nervous about everything that goes along with having a firstborn turn 16. It all started like this…

Eric:
Our 15-year-old son Landan began complaining of leg cramps in the middle of January 2011. His new year was full of events and activities at high school including winter percussion and baseball practice. Since this was the beginning of a new season, we assumed his leg cramps were due to his rigorous physical exertion as an athlete. We treated his condition by increasing the amount of Gatorade he drank and eating bananas. Next we massaged his legs at night and encouraged him to take warm baths to soak his muscles. The leg cramps increased and he complained of not being able to get his legs to move correctly when running to first base. His teammates began to laugh and told him he looked funny running. We still thought simple leg cramps and also tried ibuprofen. We had no idea the surprise that was coming.

Landan:
I remember having leg cramps during my baseball practices every time I tried to sprint. At first they were mild, so I shook it off thinking I was just out of shape this new season. As they increased I convinced myself not to worry, this had to be normal, and my body just wasn’t used to these rigorous workouts. I began adding extra stretching time to my routine before practicing and resting during my off time to increase my energy level. I really hadn’t noticed the progression of the cramping until I began to cramp during a slow jog. It was not extremely bad, but it just didn’t feel right. I remember bending down on one knee to pretend I was tying my shoe to take a break, conceal my cramps, and regain my balance. The cramping was more frequent and starting to limit my activity. On Saturday, I told my coach I couldn’t bat at our first scrimmage because I might cramp running to first base so he put in another player. As I was studying on Sunday, I got up to grab a drink and my entire body froze for a few seconds. I felt like I was going to black out so I lay down on my bed until I felt better. Later that day I was planning airsoft with a few friends and I started to cramp when I was walking forward, but for some reason I had less cramps and it felt better to walk backwards. My friend Luke was starting to question my actions and movements.

Eric:
On Monday, I received a panic call at work from my wife who said Landan had collapsed at drumline practice and she was taking him to the ER. When I met them there, Landan was able to walk but he had this glazed look on his face. He did not look right. In the ER, they started to work him up and the initial thought was that he might have had a seizure. He was able to communicate clearly and he seemed to be all right. They drew labs and asked for a urine test. I walked with Landan down the hall to the restroom. He seemed fine and walked normal. We started to walk back down the hall towards the room and that is when things got unusual. All of a sudden his body became stiff, his fingers and hands curled under, and his eyes were glazed. He continued walking in a zombie like trance. It was really scary. The ER physician was standing outside the room as Landan kept walking towards him. At this point, they still suspected seizure activity so they ordered a CT scan of the brain. Once all the test results came back, they diagnosed him with hypoparathyroidism. He was transferred via ambulance to Valley Children’s Hospital and this was the start of our new journey into the unknown. It was really tough as a parent to be following behind an ambulance with your child inside.

Landan:
I felt all right Monday morning as I headed to drumline practice to march with the heavy base drum. One minute I was marching and then I froze up, dropped the drum, and fell to the ground. The instructor thought I had a seizure so he called my mom. She took me home and I lay on the couch. I remember thinking it was nice to come home to take a break and I was happy to get out of practice. I really didn’t think anything was seriously wrong with me. My mom gave me some water while I was on the couch and then I tried to stand up. I felt the cramp coming on, my hands locked under, and then I tried to stand up. I felt the cramp coming on, my hands locked up, and then I went back on the couch. My mom said I was gone for a few seconds as she kept calling my name. I could hear my mom yelling at me, but I could not respond. Mom said we are going to the hospital right now. I thought something was wrong with me, but I didn’t know what. I have a hard time remembering the first hospital events. I remember the ambulance drivers coming into my room and strapping me onto the gurney. During the ambulance ride I asked if they could turn on the sirens, but they said this was not an emergency. The hospital room at Children’s was small in the ER, I was exhausted, and nobody was explaining to me what was going on. I still was not thinking that I had a serious condition. That night they finally started me on IVs and at this
The next morning was my birthday and I walked to the bathroom really slowly, but I was already feeling stronger. The nurses had a Humpty Dumpty sign on the door because they thought I was at high risk for falls. The physician explained everything to me and said they needed to bring my calcium up slowly so I would be in the hospital all week. Because I had an unusual diagnosis at the hospital, there were always various residents and doctors coming in to look at me. I played video games and had a lot of visitors. The nurses kept saying how big I was at 6’1” and 160 lbs because they normally had smaller kids on their floor. I thought it was funny to be taller than all the nurses. They gave me a red remote control race car my last night in the hospital. I was bored that night, so I surprised the late night nurses by racing the car by their nursing station. They were startled when the car ran into their desk instead of racing by as I had planned.

Eric:
Children’s Hospital did a great job. The physicians and nurses were wonderful. My wife and I were disappointed that this was a lifelong condition, but we were thankful because it could have been worse. Follow up visits with the physician after the hospital discharge revealed that Landan had Autoimmune Hypoparathyroidism. We have no family history of this condition. He was on Tums and Cacitriol, but we changed the Tums to oral calcium to help with compliance and tolerance. Our other two children were tested and were negative.

Landan:
I took the next week off of baseball and then felt normal when I started back. I thought to myself, wow I can run again and I finally felt normal and healthy. We went to UCSF that summer to see a pediatric endocrinology specialist and it confirmed that we were doing all we could do for my condition. When UCSF said they see about one patient per year with my condition, it made me realize that I have a rare condition, especially the autoimmune part. I adjusted to taking my medications twice per day and I just told myself that it is just like remembering to take vitamins every day. Taking my medications became a natural part of me and I don’t think twice about it anymore.

Eric:
We started researching hypoparathyroidism on the Internet and were very thankful for the organization and support group. We finally celebrated his 16th birthday two weeks after the hospitalization and we called it a “strong” 16th instead of a sweet 16th birthday. Landan continued to play football and baseball through his senior year and was able to maintain a good GPA. We did notice that he required more rest than before his diagnosis. He could still do the things that he enjoyed like baseball, football, snowboarding, wakeboarding, and working out at the gym. He was accepted into college after high school at Cal Poly, San Luis Obispo, California, and he just completed his second year. We are very proud of him.

Landan:
My advice to others is that this diagnosis can seem scary and overwhelming at first when the physicians are telling you this will be life long, but you learn to adjust and it becomes part of your new life style. You have to try to make the best of it. You can do anything you did before, but you just have to plan ahead and take your important medications. I made a rookie mistake my first summer when my family left for a 10 day vacation out of the country. We had driven over an hour away from our home heading to the airport when my mom asked me if I brought my medicine. I couldn’t believe it but I had forgotten them! My dad was upset because we had to turn around and go back home to get my medications. We still ended up making our flight on time and our family still remembers that moment.

Eric:
It has been over four years since we came into the world of hypoparathyroidism. My advice to others is to be diligent with your medication regimen and find what works for you. There will be ups and downs with this process. We have noticed Landan’s decreased energy requiring more rest and some memory loss at times. His current medications are calcium carbonate 600mg plus Calcitriol .5mcg in the morning and calcium carbonate 600mg plus Calcitriol .25mcg at night. We are interested in exploring Natpara to see if this could improve his quality of life. We have not been able to attend the yearly conferences because of conflicts with his final exam schedules. I want to sincerely thank Jim Sanders for all he has done for patients with hypoparathyroidism and without his efforts this would seem like a lonely journey.
We enable people with life-altering conditions to lead better lives.

As leaders in the development and marketing of orphan drugs for genetic diseases, Shire brings hope to those with rare conditions.
BRAIN FOG, BRAIN FOG, WHAT AM I GOING TO DO?

All of us worry about brain fog. It is a symptom of our condition of hypoparathyroidism and not something to be taken lightly. However, that is exactly what we are going to do here. If we can keep a sense of humor about some of the things that happen to us it helps our moral a great deal.

Below you will see a funny set of Brain Fog Day Reminders by Iris Carden that Carole Sanders found and got permission to use. You will also see a brain fog story told in a poem by Nancy Watson. We would love to have you send in to us your funny stories about brain fog, and we know you have them, but there is no need to get poetic unless you wish. We also would like for you to come up with some cute one-liners to add to Iris Carden’s list. We have started you off with a few from some of our members below Iris Carden’s brain fog reminders, but would like to hear from you. We will publish as many as possible in the next HypoPARA-Post.

Send your entries to James Sanders: jsanders@hypopara.org

BRAIN FOG DAY REMINDERS

By Iris Carden
(Used with permission)

- Electrical appliances work best if turned on
- Children and pets need to be fed
- Coffee makers need water added
- That alarm you set means something
- Yes, your keys are somewhere
- You do need to write it down
- Check your phone for appointments
- Don’t rely on your memory – it’s not working
- Get someone to check you addition, i.e. math
- Find out if you took your pills
- Have a nice day!

SOME FOGGY THOUGHTS FROM SOME ASSOCIATION MEMBERS:

You’ll find it eventually – keep retracing your steps. - Elura Coren

Food cooks faster if you turn on the stove. - Nancy Caldwell

If you have to sit out errands, DO IT! Pace yourself. - Cindy Shriver

Thank God your head is connected to your body or you would have lost it a long time ago. - Melissa Pickrell
Brain Fog
By Nancy Watson

Brain fog, brain fog, what am I going to do?
I’m all ready to leave for work, but can’t seem to find one shoe.
All that’s on the closet shelf is one blue pump and a hamburger bun,
Where’s my other shoe, oh, what in the world have I done?

“Retrace your steps”, my husband says, “and in all the rooms explore”.
You know last night you had both shoes on when you walked in through the door.”
But, why do I have a hamburger bun where my other shoe should be?
We didn’t have hamburgers for dinner last night; it makes no sense to me.

Let’s see, I took them off at the entrance and was carrying them to put away,
Then I stopped off in the kitchen to see how Sam’s homework was coming that day.
“Hi mom”, he said, “I’m doing great, but do you remember what you said?
On your way home from work today you’d stop and get me some bread.”

Oh, oh! Brain fog, brain fog, what am I going to do?
I had completely forgotten about the bread, and now I’m a bad mom too.
“But mom, I can’t make P B and J when you didn’t get any bread?”
Sure you can, I’ll help you, and we’ll use a hamburger bun instead.

Aha, finally I’m getting somewhere; I think I’m on the right track.
I went over to the drawer, bent down and pulled out the hamburger bun sack.
Peeking out of the hamburger buns was the toe of my other blue shoe.
How in the world did I do that, and where had my brain skipped off to?

Brain fog, brain fog, what am I going to do?
I guess I’ll just have to laugh at myself and keep a positive attitude too.
I’m sure this won’t be the last time my brain goes off the track.
So, grin, bear it, and for heavens sake, throw out the dirty bun sack.
Recently I went to an informational meeting sponsored by Shire about Natpara, a new drug that may be able to help my hypoparathyroidism be managed more effectively. I was pretty skeptical going into this meeting and actually was pretty nervous to attend, but decided to go because I wanted to educate myself on all options available on this rare chronic condition.

Although I found myself and my husband to be the only ones in attendance at this meeting, I was put very much at ease and was presented with all the information in a presentation that, although less formal, was presented as though there could have been 100 people in the room. I was able to have every question I had answered, the information was elaborated on and I was asked questions about my individual case as well. Although I was not able to be given medical advice, I was shown the ways in which Natpara would be able to help me and I left feeling educated and empowered.

I have since talked with my endocrinologist at the U of M about the drug and she has paired my care with another endocrinologist there who specializes in bone and mineral care and who is certified to prescribe Natpara should we determine it is right for me. In the long run, even if I am unable to successfully take Natpara, I feel that this was definitely a worthwhile experience and that anyone who has heard of this treatment should go and become an advocate of his or her own care.

SHIRE NATPARA PRESENTATION IN GRAND RAPIDS, MICHIGAN

By Sarah K. Claus

My name is Nicole Morris and I attended the Hypopara Luncheon Seminar on Wednesday, October 14, 2015, in Atlanta, GA. The keynote speaker was Dr. Isaac Sachmechi, Chief of Endocrinology at Queens Hospital Center in Queens, New York. In addition to myself, there were five other patients and caregivers in attendance. There were also two representatives from Shire. One was the southeastern rep and the other was from Maryland.

Dr. Sachmechi began with a power point presentation that basically covered what those of us already on Natpara had either heard from our doctors or read in the booklet from Shire. There wasn't a lot of new information presented to those of us already on the medication. A few statistics were given that I hadn't heard before. The doctor was obviously focused on the benefits of the medicine and he tried his best to stay away from any of the potential negatives. Of the four Hypopara patients in attendance, myself included, three of us were already on the drug. Obviously, the patient not on the drug had questions, but I felt as if those of us already on Natpara and the two Shire representatives in attendance answered more of her questions than the doctor. One question asked was about test strips for Hypopara patients to test our own calcium, similar to what diabetics do. Another question raised by a current Natpara patient was about education for Endocrinologists and doctors in general, on Hypopara and Natpara. The representatives from Shire mentioned the possibility of a similar informative session for medical personnel.

The two representatives from Shire seemed very genuine. They were limited on what they could say because of FDA regulations but they tried their best to answer questions and set our minds at ease over the changes coming to the company and our Care Coordinators. I personally thought they seemed caring and really were interested in what we, the patients, had to say about Natpara and our experience on the drug so far.

Overall, the seminar was more interesting than informative. I met some other Hypopara patients, which for me was the highlight of the day since I've never met anyone with this same issue. I enjoyed the luncheon and would recommend it to anyone thinking about beginning Natpara.
Don’t forget to register for the 10th International Conference on Hypoparathyroidism to be held June 2-4, 2016, in Jacksonville, Florida!

We will be celebrating World Hypoparathyroidism Awareness Day on Wednesday night June 1, 2016. There will be a reception in the Hypopara Hospitality Suite overlooking the beautiful St. Johns River in downtown Jacksonville with live music on the outside patio with refreshments.

Register at https://www.hypopara.org/support-services/conference-info.html
On behalf of Visit Jacksonville and the City of Jacksonville, I would like to welcome you to our beautiful City! We consider it our privilege to host the 10th International Conference on Hypoparathyroidism, and hope the event is a huge success and our city makes a wonderful impression on all the attendees and guests.

Perfectly positioned along the Atlantic Ocean in Northeast Florida, Jacksonville is the perfect site for your convention, whatever the season. With year-round sunshine and delightful weather, the largest urban park system in the nation and a nationally recognized Art scene, Jacksonville is the place to be when looking for a luxurious yet affordable destination.

Beyond the meeting room, the possibilities for a memorable experience await you here. The “River City by the Sea,” offers hundreds of unique and historic meeting venues, exciting offsite destinations, 21 miles of stunning beaches, over 70 beautiful golf courses, mouth-watering waterfront dining options and modern and luxurious accommodations ready to make your Jacksonville experience a remarkable one.

To learn about all the exciting events happening in Jacksonville during your visit, as well as a list of unique sites to explore and dining/nightlife options available go to www.VisitJacksonville.com.

We know you are going to have a great time, enjoy and be sure to come back!

Sincerely,

Paul Astleford, President & CEO, Visit Jacksonville
Stuck for what to give for the holidays?

Check out the Hypopara Shop for all things Hypopara Awareness! We have T-shirts, Hypopara Awareness ribbon pins and lapel pins, and wristbands.

To shop go to www.hypopara.org and click on HypoPARA Shop.
Hello! My name is Rosella Tinn, I am 44 years old, and I have shared my life with HPTH since the 15th of March 2004. In 2001 I found a pea-sized lump in my throat, which over the next 3 years kept growing. I had been referred to a thyroid specialist who saw me once a year and said I was being paranoid when I suggested a scan of my neck. In October 2003 I happened to see a different endocrinologist, the usual one was on holiday. He told me to get a scan ASAP. I got one arranged through my GP. At my scan I was told I had no form of autoimmune thyroid disease; rather there were 5 tumors. I was very shocked.

By the time my endo came back from holiday I had undergone a CT scan and FNA, which came back positive for cancer. And, I was already scheduled for surgery.

Prior to my operation I had gone on-line to see what thyroid cancer entailed. I saw one sentence that stuck with me: If you retain 2 or more parathyroids, you will be fine. If not, your quality of life will never be the same again.

The morning of my operation my surgeon came to have a chat with me. He promised that he would save as many parathyroids as possible. It turned out that my cancer was stage 4, and it had invaded my trachea and lymph nodes. Three of my precious parathyroids were engulfed by the tumors. My surgeon only managed to save one.

Since then my life has been a daily struggle, both physically and mentally. Normality, which most people take for granted, has become an alien concept to me.

I am almost constantly symptomatic. I can’t trust my own body. With HPTH you can feel tolerable, where despite being symptomatic you can still do stuff, for a few weeks or months, then, BAM!!!! Something changes and you end up back in the emergency room in a life or death situation. We HPTH folk never know when this is going to happen! Normally it happens at the most inopportune moment. For me it was always at night or in the early morning.

I can’t describe the level of vulnerability that I feel. It took me a few years to figure out and that is what was upsetting to me. I am very blessed in that I have a wonderful caring husband who actually listens to me and helps me see my problems from different angles.

So, in these 11 years I have had to re-define my “normal”. Normal, for me, is constant flux. I liken it to a seesaw. One level goes up, the other comes down. There is no equilibrium. No balance.

A good day for me now is one not spent on the sofa with arrhythmia, purple lips/tongue, vertigo, vomiting, or severe muscle spasms. On a good day I can have a shower and do some cleaning. Or, I go for a walk, I can type, cook a meal or do my crochet!

The one good thing about this whole situation is that it has showed me who I am! And, I’ve found out I am much stronger and a lot more stubborn than I ever knew! I just don’t know how to give up. Some days this seems to be a good thing, others, not so.

I promised myself when I found out I had cancer that I would NOT become a miserable person. I would NOT let this cancer take away my joy and change my essence. Prior to having cancer I had lost both my parents.

This had already made me realize it is people, and not things, which matter. I won’t say it hasn’t been hard! In fact, I have fought tooth and nail to retain my identity. I want to be Rosella, and not a victim of cancer and the resulting HPTH.

I used to work as a freelance interpreter. But, as my job demanded a lot of...
travelling and thinking, I had to give it up. HPTH causes dreadful brain-fog, where one just can’t think at all! Not good if you are doing face-to-face conferencing…in more than one language.

My savior has come in the form of PTH. Teriparatide 1-34, a daily subcutaneous injection, which has given me the ability to do even more, on a good day. It took me 6 years of letter writing to finally get it. When I first mentioned it to my endo, he yelled at me! Said I had no idea about anything and to get used to being as I was, a veritable wreck.

So, I started writing to him. A good friend told me to “put it in writing”. If you send a letter to your specialist it goes in your file and they can’t deny it. Otherwise, they can say nothing was ever mentioned. I wrote to my endo regularly detailing my decline, which no doubt annoyed him!

As PTH was not, or is not yet, licensed in the UK to treat HPTH, I had no idea how to go about getting it. I wrote to the Chairman of Eli Lilly (the manufacture of Teriparatide). Then, I wrote to NICE (National Institute of Clinical Excellence), who deal with allocating drugs. NICE advised me to write to EUA (European Medical Association). All of these people were very nice, but said it was not their decision. Only my endo could prescribe it, if he really wanted to. My condition kept getting worse and my kidney function was deteriorating. I was having nothing but bad days. Just a sick waste-of-space stuck on the sofa. I could see the hurt and fear in my husband’s eyes as he looked at me. It was breaking my heart.

Then, quite by chance, my final 6-page letter intended for my endo (detailing all the clinical negligence for the past 6 years and my poor future prognosis) actually ended up in the hospital complaint department. They passed it to the hospital board. I had said at the end, if my kidneys failed, I would sue.

The next thing I know I get a phone call and there is a prescription for PTH waiting for me!!!!! I sobbed my eyes out! I just could not believe I’d finally won! This battle for the elusive dream of PTH was finally over.

PTH is way better than my old meds (Alfacalcidol or 0.25 hydroxy vitamin D), though not perfect. My kidney function has improved drastically on it. And, I am free of the 2 a.m. dashes to the emergency room. Last year we actually went on holiday to Scotland! Our first ever holiday in 11 years. This year we went away for a lovely week in Cornwall. We packed my PTH in a cool box, and off we went! Prior to this wonder drug I could not go anywhere. Firstly, as I felt too sick to travel, and secondly, I was too scared to go too far from the hospital. Since getting PTH, I’m free to travel! I still have bad days, but in general, my quality of life has improved since getting PTH.

And, I’m back to having a career! I am now a freelance designer. I mentioned I love to crochet. Since last year I have had 9 patterns published in a British crochet magazine, Inside Crochet. I’m hoping to start work on a book of my patterns soon!

Apart from woolly chickens, I also design adult and children’s garments. Basically I crochet just about anything and everything! You can see more of my patterns/work on my blog [www.woollycluck77.blogspot.co.uk](http://www.woollycluck77.blogspot.co.uk)

So my message to all my fellow HPTH folk is, DON’T EVER GIVE UP! Be proud of who you are!
My story starts from my birth in 1954, but I’ll wrap it up quickly. I was born with idiopathic hypoparathyroidism. Idiopathic means the actual cause of my disease couldn’t be determined. I really didn’t know about it, no one told me then that I had Idiopathic Hypoparathyroidism. But, growing up wasn’t easy. My parents had 3 other children besides me and it was hard for them. I was the second child and I was not perfect. They labeled me that way and that’s how I felt. I got teased a lot for being so small and I was called retarded. People are always telling me retarded just means slow, but to me it meant rejection. The way people said it just made me feel different. I didn’t think I was different. I did things like everyone else did, but I guess not to their liking. In school I got left behind. I started in a regular school; then I was sent to a special school and then back to a regular school. Needless to say, I hated school. It was always a struggle to try and fit in, and often I didn’t.

There were lots of hard times growing up having hypopara, especially when no one knew what I was going through inside. I was sick a lot, but had no fever so people always questioned whether I was really sick. There were no doctors back then that knew much about hypopara. I itched a lot, had tingling, and I cried a lot because I hurt. I was born with rotten teeth and my teeth always hurt. I still have my baby teeth in a little keepsake my mom gave me. Going to the dentist made me cry and no matter what I did I had teeth problems from childhood into adulthood. I have a permanent partial on my bottom teeth. All of my bottom teeth had to be pulled and it was one of the worst days of my life. My hands crippled up badly and I didn’t know why, and that occurred when I was an adult and married to my husband.

The cramping of my hands actually started in my teens. Sometimes they formed a claw-like position that was so painful I could not move them. I also had extreme eczema on my hands. In order to get rid of the bloody rash I wore cotton gloves with special cream on them all through my teen years and into my married adult years. My husband and I thought it was because of the airplane factory I worked in for 15 years. They used lots of chemicals and I know it irritated my hands. I did quit working at that place after I married because it was making me sick. But, that’s where I met my husband and I’m so thankful for him.

There were also a lot of fun times growing up. I remember meeting my best friend Lorraine, whom I call Rainee, in 1968 in Sun Valley Junior High School in Sun Valley, California. Sitting in class Rainee was cattycorner to me in another seat. We started talking and she asked if I wanted to join her at lunch. We have been friends ever since and we have been through the ups and downs of life together. I love her like a sister and she knows more about me than any other person except God.

One night in my teen years both my parents happened to be out in the living room. I was really hurting that night and my parents couldn’t do anything to help me. They were both drinking beer, so they gave me a drink to see if it could calm me down, which it did. I don’t think now it was a wise thing to do because by the time I was seventeen I was an alcoholic. I also did drugs and alcohol through the 70’s and 80’s in an attempt to get sleep and to numb the horrible pain in my body. I have now been sober 16 years.

My mom finally took me to see an endocrinologist when I was 17. The doctor tried to help me, but I really wasn’t helped much. I hadn’t started my period yet and he had me take Premarin and Provera. I finally developed a period by the time I was 22. They also told me I couldn’t have any children and that really hit me hard. He had me take vitamin D and Tums, but I still had claw hands and I still cried all the time, and I still do. I was still sick with too high calcium or too little calcium and had that incredible itch that totally made me crazy. My parents tried to do their best, but I still suffered the unknown. I almost took my life.

Why did I almost take my life? Well, the pain of hypoparathyroidism was just too much, and still is at times. I never slept well because of the painful itching, the tingling pain, and the cramping hands. It has always been worse at nighttime. I was drinking a six-pack of beer a night just so I would pass out, but that really was not sleep. I just kept getting worse and worse and was always sick. I couldn’t take it any more. There were some things I did because of my situation because I knew nobody cared and those actions just proved it. At least that’s what I thought.

Then I started thinking about my life. Why am I here? I needed some answers and I asked Christ Jesus into my life around the time of the September 11, 2001 attacks, 9-11! After Papa God started talking to me things got better. For a change I wasn’t focusing on how I felt. It’s been a day-to-day journey. I won’t go into everything here because it’s my whole life that has been spent with this intruder, but things do get better and better.

I had my first big crash in 2006. A really bad cough was going around the Bishop, California region where I live. It seemed like a lot of people were coming down with it. I remember coughing to the point it just hurt so much it made me vomit. I was hot with fever and no one seemed to believe or understand how sick I was. I remember be-
One of my many crocheted projects I enjoy doing. To keep myself busy these days I have developed projects. I love Facebook and I have a lot of friends on there. I also love taking photographs and sharing them on my Facebook page.

I started my own Facebook group called Linda Maxfield’s Knitting & Crocheting group everyone is welcome. If you enjoy those crafts please come and visit or share. Kitties are another of my loves. My Manx cat named MarYgold is 4 years old and is such a blessing. She has her own site on Facebook too – MarYgold Peanut Maxfield. For fun I enjoy playing the piano, guitar, and I am learning the ukulele some friends gave me. I also enjoy doing photography around the beautiful Bishop, California area. These projects keep me focused on something other than my hypopara.

I want to thank my friends Paula and Rainee for encouraging me to tell my story. I also appreciate the support of my pastors; church family; and my beautiful husband, best friend and caregiver Jim. Along with my parents, grandparents and siblings they have pushed me to the point I am not giving up. Remember! There is always hope and with God nothing is impossible! Hope to see you on Facebook.

God he didn’t and the swelling went down. I found myself the next day in bed in a hospital room with friends coming in saying, “What happened to you?” They couldn’t believe how sick I was. It did get worse. My calcium numbers were jumping up and down, I had the incredible itch thing going on, and I was almost into pneumonia. Then my right leg started cramping and I thought, “Oh, no…what is happening?” I was in full-blown tetany.

I don’t remember three days of my life, except being in a very quiet place where all I saw was white. The brightest white I ever saw. And, it was silent and peaceful. I thought, maybe Heavenly white I ever saw. And, it was silent except being in a very quiet place where all I saw was white. The bright

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For every disease, there are seven billion different treatments.

Even using the same treatment, results vary greatly as people have different genes. We are endeavoring to develop treatments to match each person’s DNA, called “Personalized Healthcare.” As everyone is different, the same treatment doesn’t exist. There are as many solutions as there are people.

Advancing to a new age of one treatment per person.
The mission of 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