VIEWS AND PERSPECTIVES

A compilation of comments and insights from

patients, readers and advocates

The survey question

From time to time we ask our readers for their opinions into issues that can help the community as a whole. Today, we have a one question survey about experiences with the pituitary disease diagnosis process. We will use the observations and comments for an article so everyone can benefit from the collective insight .   You do not need to provide your contact information and your response will remain anonymous.

Question:

Many of you have shared your experiences with the pituitary disease diagnosis process. It is typically described as a lengthy, often frustrating process with frontline health professionals and primary care physicians who generally miss the signs of pituitary disease. In your opinion, what could be done, from a patient's point of view, to help ensure primary care physicians and other frontline health care professionals put pituitary disease on their list of possibilities? Please write your answer in the space provided below. You may write as much as you like.

Selected responses:

I don't know how patients can help answer this question! When we first seek help we don't have any idea that our symptoms are related to a pituitary condition. At least, I didn't! I think we need to train the doctors better. In my case I had DI but my MD simply told me to suck on candies at night to help my thirst. That MD had no idea what DI thirst feels like. This is a thirst unlike any other. I was drinking about 20-23 liters per day but the doc told me to suck on candies... I don't blame him... he had no idea. The word "thirst" should send up certain flags but it didn't. I also have Diabetes Mellitus, so it's understandable that a lazy MD simply thought my thirst was related to that. As I said I don't blame him, but there should be a way for a system to be set into motion when patients complain of severe thirst and urination.

There is a need for well-trained GPs and Internists, PCPs. I was not diagnosed until I was 61. Although I was given thyroid medicine at the age of 19, I continued to be symptomatic. Doctors gave me diet pills! When I complained to another PCP that I could NOT stay awake long enough to cook a simple meal or even drive to her office, she told me to just get more sleep. She said I should rest in her front office until I thought I could drive home - after I told her no amount of sleep was enough. These first-line doctors have a tendency to dismiss you if you are young. They do not hear you. I once told a doctor I had difficulty swallowing and she replied, "NO, you don't." So I think these PCPs, et al. need to learn to listen better and exercise critical thinking. My veterinarian finally called me and talked to me for three hours - insisting I ask for Armour thyroid. I had to see a certain endocrinologist to get it - no other doctor would prescribe it. Ten days after I started taking it, I felt like the world was a beautiful place. I was in misery, not living up to my potential, for all those years I was not properly medicated. Dr. Blevins at UCSF detected and treated all my hormonal deficiencies when I was almost 61. My number one complaint is that nobody listened to me when I told them how sick I was. When I complained of pain, one doctor told me to drink vodka. Just a month ago my doctor tried to tell my avocado was not very nutritional! Her assistant looked it up and corrected her. She would not listen to me. Those first-line physicians need to listen, and think about what they say before they say it. I don't go to the doctor unless I have a problem I cannot handle by myself. So telling me to drink, or that I don't have a problem swallowing, etc. - they are not paying attention to what I am saying - they are dismissing me. What is missing with these doctors - not listening, not caring, not knowing how to treat, not having respect for me? I don't know where to begin. My frontline physicians were a huge disappointment and I suffered many years because of their apathy/lack of knowledge or caring... not sure. My life has been greatly improved - but I am an old woman now. Thank you for asking this question. I hope you get an answer and can cause a paradigm shift here. It is sorely needed.

All Dr's medical staff should have to study a section just on pituitary gland and the problems it causes ...after all the pituitary is one of most important parts of the body and the doctors etc should of studied in depth ...the same as they do for lungs ,hearts eyes ....the pituitary seems to get swept to the side lines...for months I saw many Dr's some said I had the flu when I had diabetes insipidus caused by tumour ...a Dr said stop drinking so much you've had the flu and now it's your imagination making you think your thirsty...I was told I had ME ...I was told I need blood test's as they thought I was diabetic ...but none of them was right ...It went on about 6 months ...being misdiagnosed. ..then I saw another Dr and as soon as I told him my symptoms he sent me for a brain scan ...and they found the tumour .....I must of seen 8 Dr's before that ...none of them had a clue .....then even after diagnosis I saw a Dr and he said how much insulin are you on I said I have diabetes insipidus..he said yes I know ...how much insulin do you take ....he wouldn't take any notice so I walked out.

General practitioners need more training and awareness on pituitary disorders, this could be done by well informed official awareness groups or included in their own continuing professional development update training.

I'm a 58 year old man. My first certain sign of a severe endocrine problem was in the summer of 1994 when I was 37, when I fractured a couple of ribs with little trauma to cause them. It took me until January 27th of 2003, so about 8 1/2 years, to get a correct diagnosis of hypopituitarism, adult growth hormone deficiency and secondary hypogonadism. During those years I transitioned from an extremely active, very fit amateur triathlete, professional award winning architect in private practice, to a disabled, feeble, severely depressed and suicidal wreck. Getting to a diagnosis over those 8 1/2 years and living through all of the secondary conditions (13 of them) that ensued as a result (but where never treated properly because of the lack of accurate diagnosis) cost me nearly all of my million dollars of personal assets I had built up from zero. Over those years I worked face to face with multiple primary care doctors, multiple endocrinologists in private practice, the heads of the endocrinology schools of Stanford University, the University of California, Davis and San Francisco, Harvard, and an array of about fourteen specialists at the Mayo Clinic, Scottsdale. None of this 8 1/2 year extreme effort produced an accurate diagnosis.

By the time I spent a month at the Mayo clinic in the summer of 2001, I had fractured my spine and ribs about four dozen times from severe osteoporosis, I was living on Vicodin, multiple varieties of antidepressants at different times prescribed by a total of 6 psychiatrists , Ambien, Fosamax, statins, calcium (with no vitamin K2-bad treatment), many forms of vitamin D, and a host of other undesirables. When I was finally, correctly diagnosed in 2003 (by Dr Eugene Shippen in Pennsylvania) and I started injecting human growth hormone (HGH) and human chorionic gonadotropin (HCG) to attempt to replace these deficiencies in my body due to my malfunctioning pituitary gland, my body went through months of dramatic rebuilding where I felt like I had a factory with a huge furnace burning inside me. I swear I could literally feel the reconstruction occurring inside me. Within six months I had shed ten of the thirteen diagnosed conditions I had when at the Mayo Clinic and I had eliminated all of the medications I had been on except the ones related to the bone rebuilding and the pituitary disease.

I think there are a number of things wrong in the practice of mainstream endocrinology that caused me to go through this hell, and what prevented all of the experts I worked with except for one to interpret the lab results and symptoms correctly. I'm sure that if I were thoroughly trained in endocrinology I would see this differently, but from my perspective as a chronically mis-diagnosed patient, here are the issues:

1. The lab results are not properly age, sex, fitness-level and genetically defined. Some of this has to come down to the experience of the physician, I'm sure, and obviously our knowledge of genetics needs to be developed dramatically. But even in 1996, "normal" for me as a 39 year old extremely active professional and a competent amateur athlete capable of running a marathon through the mountains above Tioga Pass over 10,000 feet (even with three broken vertebra and two broken ribs), is not the same as "normal" for a retired, sedentary, seventy-five year old. The inability of all of these extremely skilled and knowledgeable doctors in my case to interpret the lab results adequately is what ripped apart my life. The labs rarely changed much over the 8 1/2 years of my odyssey. What saved me was one experienced doctor who refused to accept borderline "normal" lab results, and who had the balls to think for himself, use his training, and not be a drone in the endocrinology machine. Inexperienced primary care doctors will never be able to accomplish this and send you off in the right direction to test for pituitary disease. The front-line docs have to have a significant improvement in the written interpretation, categorization and differentiation of the black and white lab results staring them in the face at the time of the appointment with the patient (+/- 15 minutes usually, for a hideously complex disease)!

A brief note before points 2 and 3: I owe my life and my daughter's life (with cystic fibrosis) to the advancements created by the pharmaceutical companies. They have done and continue to do a remarkable amount of good. That said...

2. It boils down to research driven in the right direction to create this level of knowledge, and not typically in the direction of the profit motive! In order for us to have the differentiated lab results in the written reports reliably accessible to our doctors, we have to seriously point our research efforts in this intentional direction. Unfortunately, American endocrinology and the focus of its' doctors is typically directed by the pharmaceutical companies. I learned this ugly lesson the hard way. I am not exaggerating and I am not a conspiracy theorist. The pharmaceutical companies drive most of the research in the direction they need it to go, and they have a massive impact on the funding and direction of the education of our clinicians and researchers in our universities. This is not going to effect the change that has to occur in order to solve the problem.

3. ALL of the endocrinologists I worked with to try and get a root-cause diagnosis (prior to me finding Dr Shippen) told me EXACTLY the same thing in proper drone fashion as prescribed by the pharmaceutical companies, I kid you not. Essentially, it was always "Go take your Fosamax, calcium, vitamin D, painkillers, Ambien and antidepressants, and accept living this way, because all of us experts agree". Had I accepted their advice I would have been living in a wheelchair, disabled from chronic fractures, in severe suicidal depression until I decided finally to end the pain (Note to Doctors: antidepressants don't work well on patients with pituitary disease as the root cause of their hormonally induced depression). I did not accept their advise, and as a result I have had many good years of active life. The lesson here is that our doctors must be able to think and act independently of the pharmaceutical companies. This is not the way mainstream endocrinology is in today's world. This has to change!

4. We live in a big world, beyond the borders of the USA. Doctors and researchers and medical associations and legislators and government regulators and insurance companies, listen to, pay attention to, and act upon the knowledge and advancements developed outside of the USA. We are not always the leaders in knowledge of medical advancements!!! Get over it, be a part of the world. We could improve medicine dramatically in the USA if we would open our eyes to the knowledge of others.

I hope sincerely that other people benefit from my experiences. I live on the belief that compassion for others and the benefit of others is of the utmost importance for us all, and this is why I am always willing to tell the details of my story. I hope others suffer less than I have.

Make lab testing for pituitary hormones routine requirement. Make testing for ft-3 and ft-4 a requirement along with TSH. My TSH was showing a false normal. If my doctor would have drawn labs for t4 and t3 he may have notice a problem years before when my complaint was fatigue and I had all the symptoms of low thyroid. Special education for doctors regarding the pituitary maybe. How many cushings patients are told they are fat when they have every classic sign of cushings. I know a lady now that has a tumor on her adrenal gland causing cushings and her doctor is doing nothing. Told her to exercise more and eat less.

Education, education, education. Now that I have a diagnoses I try to educate all healthcare professionals that I see. The one thing that I tell them is that if they suspect a person may have acromegaly send their patient to the right endocrinologist. Don't just tell them to see an endocrinologist. Do the research for them and find a dr. who specializes in the condition. If not it may continue to be years before they get the proper diagnoses. In 1994 a pituitary tumor showed up on an MRI. My GP sent me to a neurosurgeon - my complaint was headaches. The neurosurgeon told me that the tumor was not the source of my headaches and I should go home and forget I had the tumor. He said that pit tumors are often found on autopsies and the People never had any bad effects from it. While that advice helped relieve the fear that I might die from the tumor I never forgot. All of us have a story - and they are very long. In 2001 I had surgery to have a then large pituitary tumor removed - still had the daily headaches. The tumor was found to be a growth hormone producing tumor. I was good for one year and headaches returned. I don't know how many doctors I told my story too and told them I thought it was too much growth hormone and they ALL told me that that couldn't be the problem. . . So education is what is needed. We need to be seen by specialists who know the condition Acromegaly. In 2015 I had a second surgery but came out with tumor remaining. Nine months ago I started on Somatuline Depot and I am happy to say it has been life changing. I am now living almost headache free. I get some breakthrough headaches from time to time but my bad days now would have been an absolutely fantastic day pre-medication! Thanks for caring!

Before my diagnosis I had no idea that we had a pituitary gland and was even more clueless about what it did! In the three and a half years I was ill, even though I saw many doctors and had many blood tests nothing was ever mentioned about the pituitary or adrenals. They did however keep checking my thyroid function, which as I have Isolated ACTH deficiency was fine.
The day after I got out of hospital I went to see the doctor (one who had seen me upto 10 times within my illness) and he said he had never even considered pituitary problems or Adrenal Insufficiency although when he looked up the symptoms online, I had them all. Also when talking about diagnosing pituitary problems, the last thing a patient needs to hear is a student asking if it could be a tumour and then noone explaining. This lead me to be even more scared during my stay in high dependancy and in the run up to my MRI scan. I feel doctors need to be encouraged to look into the rarer possiblities, okay perhaps not straight away but when nothing else is fitting, to just put it down to depression (which I actually didnt have) or an eating disorder makes the patient feel uncomfortable in coming back and "making a fuss" to get a correct diagnosis. Even now with a diagnosis the GPs I see (lots of locums) don't understand what my condition is and some have actually asked if I'm on hydrocortisone for my skin! I now try and explain my condition initially as 'like addisons' as they have at least heard of this and are aware it means steroid dependant, if i start by mentioning I have Isolated ACTH deficiency I more often than not seem to loose their interest. This doesn't fill me with confidence that they wont miss this, or a similar diagnosis in other patients. It would be nice to think that there was a process in place in which normal common problems are looked into first and then if the problems are still there, a second set of tests which do look into the rarer causes of symptomatic illness. This I feel would have saved me a few years of unexplained illness and also avoided the serious crisis that led to my diagnosis. I do feel that most of the trainee doctors I have seen have an intrest in my condition and ask many questions about my symptoms before diagnosis, this at least makes me hopefull for the future that it might be something that newer doctors are aware of.

Please do not miss my important story - Regular blood screening that picks up the pituitary hormones as well as the hormones from thr glands they affect ... such as TSH, free T4 and free T3; ACTH and cortisol, and so on. Vitamin D screening and metabolic panel as well. I was pregnant and developed issues in the third trimester due to pituitary issues. I suffered adrenal crisis and had low thyroid and cortisol. Had my bloods been more thoroughly screened more regularly during pregnancy, I may have avoided the horrific experience in my 3rd trimester that begun with daily mild headaches that got worse each day. They became unbearable and I could not function. I became very weak and sluggish. I could barely clumb the stairs in my house. I mentioned the headaches to my obgyn everytime I visited which was about every 2 weeks. At first she just said normal pregnancy hormones. But finally she said this was not normal. But by the last few weeks of my pregnancy, I was so sick vomiting uncontrollably, horrible headache, disturbing insomnia, I landed in L&D where my blood was tested. I had low sodium, elevated liver enzymes, low cortisol and low thyroid. The hospital put me on intravenous saline drip which helped a lot. I got some sleeping medicine so I could finally sleep. They brought in every specialist - nephrology, neurology, my high risk maternal fetal medicine dr, my ob-gyn, and a few others I forget. I had an MRI. They then said I have an enlarged pituitary more than the normal range for pregnancy. That is when I learned that the pituitary enlarges during pregnancy. After my hospital stay of 3 days, I went on to see an endocrinologist at almost 37 weeks pregnant. I was about a week away from my scheduled cesarian. She tested my morning fasted blood for cortisol and thyroid among other things. Again low cortisol and low thyroid. She started me on 75mcg synthroid and hydrocortisone. At the time she just thought I was hypothyroid. She was concenerd about the stress of my upcoming cesarian. On day of my cesarian they gave me the hydrocortisone intravenously. I had my perfect baby girl. I finally felt normal again. I weened off the hydrocortisone several weeks postpartum with no issues. My cortisol returned to normal. I am now 9 months pospartum. I reduced my sythroid by half in February 6 weeks ago). My last test after a few weeks on lower dose showed normal thyroid and my TSH went back up to normal range. My ft4 and ft3 did drop to low normal. I retest in mid April. I feel fine mostly. I do have some sleepless nights, so I suspect I'll be going back on higher dose of synthroid after my next blood test. I believe after my experience, pregnant women should have their hormones monitored for issues with pituitary, adrenals and thyroid. Thyroid disease can be very harmul to a developing fetus which relies on the mother's thyroid during pregnancy. Just like gestational diabetes screening is a regular part of pregnancy these days, so should thyroid and adrenal function. Ongoing headaches should be a major red flag to OB-Gyn to catch issues before they become near-fatal.

Understand that not all of the US is obese and overweight some ppl may actually have something wrong w them!

My diagnosis process wasn't the nightmare of others I've read. That being said, it was a six month process. The symptom that got me to seek care was a vision issue. My optometrist ultimately sent me to a neurologist who put me through the wringer and tried to make me fit into a MS mold. It wasn't until I insisted on an MRI that I was diagnosised. If my PCP had allowed me to have a hormone test when I began having problems, I would have likely been diagnosed years earlier. In both cases, I feel the doctor didn't want me to incur the higher expense test that would have assisted in diagnosis. While I appreciate their intent, the delay in diagnosis and growth of the adenoma is likely responsible for the symptoms I deal with today. I guess the health care system is really the issue!

Dentists should be more informed on the sivnz of teeth srperstion. All docs who test patients for dlerl apnea need to be xchooled on checking for symptons of acro.

When an otherwise healthy 29 year old female stops having periods, please ask why, instead of immediately prescribing birth control to regulate. This would have saved my fertility, as well as 13 years of misdiagnosis and mistreatments.

I believe this goes back to medical school. I feel that pituitary diseases get very little lecture time

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I agree most doctors do miss the diagnosis. I think having cortisol levels checked through a simple blood test when patients present with serious chronic fatigue like symptoms lasting more than 4 weeks would help patients that have adrenal insufficiency. They missed mine completely and I also must died as the doctors didn't take my symptoms seriously at all even though I visited on several occasions pleading for support. Perhaps checking all hormones within the pituitary gland via bloods would be good.

First of all, a high number of medical personnel do not know what Diabetes Insipidus is. I've had to explain it to many professionals. A nephrologist once told me even told me I was addicted to DDAVP!!! Well yeah, otherwise I'd die!

I wish there was more of an emphasis on pituitary disorders in general in medical schools. Although my docs have accepted my DI when I've explained it. I am finally seeing an endocrinologist (after 21 years of DI, who is looking into other possible repercussions from the removal of a rathke's pouch cyst from my pituitary. My neurosurgeon said, "Oops...I must have pulled too hard!" He said DI only involved taking a pill.

I ended up with DI right after the surgery so there was no delay in diagnosis. There is very little information out there for folks with DI, especially parents. With DI and the other disorders, docs and nurses need to know that the effects can vary from day to day for every individual. I was never told about water intoxication. I thought I was supposed to use one squirt in each nostril. I never had break through until I ended up back at the docs after someone drove me there.

I've seen very little literature for patients with DI explaining the ins and outs. That's why the DI Facebook page is soooo important. Even then, we have to experiment. Most of my docs tell me to manage it on my own because I seem to be doing well that way.

I'm sure many of us could write chapters for a book, but it wouldn't get published because we do not have medical degrees. It's terribly frustrating to be dealing with the medical community when the patients have to do the educating.

I am greatly fatigued many times as my meds are wearing off. Yet, the side effects are not "published" except maybe in medical journals. Because DI and other disorders are so rare, sufferers feel so alone with no one to turn to for support. There are few access points for information for those who suffer from pituitary disorders.

It would be great to have a brochure explaining the various challenges of these disorders and further references for medical professionals should they be motivated to learn more.

Thanks for the opportunity to speak out!!!

If you look for big feet and hands, or other body signs, you will miss a group where I fit in, no real features in the outside. IGF-1 should be advocated for women with miomas or fibromas, headaches, pain in the eye, fatigue, dizziness, insomnia and so many other symptoms... I guess IGF1 test is less expensive than an MRI, so it shouldn´t be such a rare exam to be asked...

I think I speak for most 'patients' with Pituitary disorders when I say that post diagnosis treatment from primary physicians or other professionals need to be more aware of what/who they are dealing with. It seems across the medical field there is a lack of understanding with pituitary disorders, this being the case it should be a more fundamental addition to medical schooling. If Drs don't know what pituitary disorder there are and how to treat patients with them then how are they expected to screen for them when they have no idea of the most obvious symptoms?

I think that if Dr s such as Endcrinologist or Nuro surgeon s put on special educating classes for continuing education for the Dr,s that they could be better informed. In my opinion Dr .s dismiss us as rare ,so they don't feel the need to be educated enough to catch this early and diagnos us! Have patients like us talk first hand to Dr .s and let us put a face with acromegaly ! They need to know how we feel and that this is a life time sentence for most of us,and early detection can make a big difference in the quality of life that we will face !Educate dentist,eye Dr.s the same way with continuing education classes.Most of us with pituitary disease would be more than happy to tell our story to any medical class or college. The pictures that we take at Dr offices to update our records can be used to note Phyical changes,alert Dr.s on what to look for ! This is one of the best ideas to me :) thank you for working on this podcast and all the hard work y'all do for all of us!!!

Personally I believe adding the igf-1 blood test, much like an AC-1 or a TSH would help a lot of people get diagnosed much sooner.

Education and Awareness play a big part in getting help from PCPs but also Specialists. The doctors don't listen. You tell them your symptoms and even show them physical proof but it falls on deaf ears. Most people know their own body and when it is off. Testing is important but if the tests only show small drops then you must wait years for levels to bottom out to finally get help. Most of the time I hear it is impossible for this or that when it comes to pituitary. I would like doctors to listen and try treatments.

Primary care physicians must learn more about pituitary disease and what to look for, especially fairly easy to spot diseases like Cushing's and acromegaly. I just had to get a new PCP because my regular doctor retired, the new doctor asked me what panhypopituitarism is... He also told me I was on too many drugs, I take hormone replacements and a drugs for lupus! This is crazy! There should be at the very least some education and continuing education on pituitary disease... After all the pituitary controls the entire body!

Mailings of correspondence on pituitary disease to their places of business. Also, documentaries on pituitary disease on television to educate the general public as well as professionals. Seems to me, most doctors and frontline health care professionals are so uneducated on this condition.

The healthcare system is the problem. Because doctors are on the clock, they don't have the time to really talk to the patient and listen to all of the complaints. Because we come to the doctor with fatigue, headaches, joint aches, etc., they usually concentrate on one or two and send us of to a consult or two. Usually testing, x-rays and what ever else they can think of. What comes back is nothing and then they're confused. If they had taken the time in the beginning, asked to see a picture of us five years ago, they would send us to the endo and we would be on our way to proper health care. It took over three years and I can't remember how many doctors and visits before one doctor said, she was going to send me to an endo and spending 30 minutes with me. She was an Air Force doctor at MacDill AFB. She wasn't on the clock like all of the civilian doctors I had been seeing. The endo diagnosed me in 10 minutes. But the damage is done. I suffer because we didn't catch it sooner. We let it attack my body for over three years and now there is no reversing the damage. I don't know how you can make primary care physicians more aware of Acromegaly when it is so rare except that maybe in the continuing educating courses that they have to take they are alerted to the picture test with people with our symptoms. With a few years of experience, it may be a perfect time to slip this in.

I have mixed feelings about diagnosing pituitary problems. I'm lucky, I was seeing a regular doctor for an unrelated health issue. While he took care of the issue I originally went to him for, he noticed and made a comment about me needing to see an endocrinologist. The doctor said I needed to be checked for another issue, he didn't elaborate, but gave me a referral to an endocrinologist. I went to the Endo and he looked at me and basically told me I had acromegaly. I have all of the physical signs of acromegaly, as a matter of fact i have been stopped in airports by doctors who were curious if I had been diagnosed with a acromegaly. I tell them I have and its under control now.

The downside I have had with doctors is dentists. I went to several dentists for regular dental work and while the dentists were filling cavities I had to bite down on the filling so it would match by natural bite; however. I couldn't bite down due to my jaw being out of alignment side to side and I my lower jaw sticks out further than my upper. I even went to an orthodontist to see what it would take to fix my jaw, the orthodontist didn't even wonder what was causing my alignment issues. This was before I was diagnosed with acromegaly. None of the dentist or orthodontists were the slightest bit curious in what was causing my jaw to be so messed up. I think dentist and orthodontists need to be educated on what can cause severe jaw malalignment and most importantly, they need to be asking questions. If the dentists and orthodontists had asked questions, my tumor could have been caught 3-4 years earlier than it was caught by an observant family doctor. By the way, this was my one and only visit with this particular family doctor, he saved and changed my life.

Include a Hormone Imbalance Checklist for patients presenting with many, non-specific, seemingly unrelated symptoms. It was this simple checklist, that I found online, that tipped me off to the possibility of having a Tumor and hormonal problems. It "should" save years of frustrating doctor visits with a quicker referral to Endocrinology for further evaluation.

Because it is believed to be more prominent then previously thought, maybe educating Dr's more about the symptoms of Acromegaly so that when a patient comes in complaining of what seems like random ailments, in comparison to a list of Acromegaly symptoms maybe a quicker diagnosis will be made with some patients. Or maybe an MRI will be more readily ordered if a patient meets a number of symptoms on said list leading to a faster diagnosis for most.