

**Understanding The Journey:
PCOS, Cushing's Disease, Panhypopituitarism
to Endocrine Nurse**



**May 17, 2018
Bonita Springs, Florida
Rebecca Brooke RN, BSN**

Disclosure

- I have no actual or potential conflict of interest in relation to this presentation

Objectives

- Recognize the signs and symptoms of Cushing's Disease
- Learn from interactions with medical professionals
- Understand the potential impact of pituitary surgery
- Consider how bad things have worked out for good on your own journey

Focus

- Look through the lens of my journey with endocrine health issues and my path to endocrine nursing

Overview

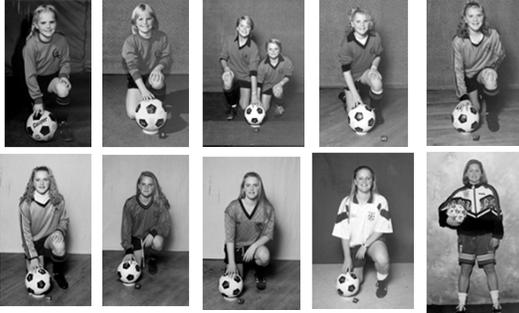
- My Story
- Basic Endocrine Anatomy and Physiology
- Signs and Symptoms of Cushing's Disease
- My Job Now
- Question period

My Story



Me... youngest of four.

Soccer career...pictorial transition



High School Transition



'89-Grade 7:
normal
menarche



Grade 8: happy
high school girl



Grade 9: still
happy



Grade 10:
happy

Grade 11:
hormonal
but happy



'95-Grade 12:
Something was
wrong

So What Happened?

- Friday May 13, 1994
 - Right knee ACL reconstruction
- Saw GP June 1994
 - "What is wrong with your face?"
- No Menses Nov 94-Sep 95
 - Active, semi-vegetarian, nothing significant on BW
- University Sept 95
 - BCP, Accutane and undiagnosed depression
 - Left university, did MOA (medical office assistant) course



Adventure

- California 6 Flags June 96
 - Ruptured ovarian cyst
 - Referred to Endocrinologist “There is nothing I can do for you. You have PCOS. You need to take the BCP”
- Europe Soccer Camps Aug 96
 - Kidney stones



Rest and A New Start

- Nanny for a year
 - Colostomy care
- Off to Nursing School Sept 97
 - Studying Pathophysiology
- New GP Oct 97
- Referred to Endocrinology April 98
 - Elevated cortisol, dex suppression, 5 day 24 hour urine collection for cortisol, pituitary MRI, adrenal gland CT
 - ALL inconclusive



Now What?

- Another Endo? – no
- Stopped BCP
 - 3 months later ... irregular menses
- Graduated with BSN Dec 2001
 - Depression ... this time diagnosed
 - Walk in GP “Do you want me to put you on the same antidepressant’s I’m on?”... Effexor 6 mos



First Job

- Mentorship Pilot Project May 02-Dec 03
 - Worked in Acute Medicine for 1.5 years
 - Developed migraines, ++ stress, BP 140/94
- Mexico 02
 - Kidney Stones on return to night shift
- Stress leave Jan 04
 - Back on meds (same walk in GP), counselling, quit job, walks, prayer

Pivotal Career Point

- Diabetes Camp July 04
 - Met my nurse mentor
- Started insulin pump training Sept 04
- Started Nadolol for continued migraines and hypertension May 05
- Diabetes Camp again July 05



Try again

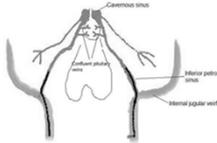
- CDA Annual Conference Edmonton Oct 05
 - Eye exam revealed 'cotton wool spots'
- Training on CGM (Continuous Glucose Monitoring)
 - Revealed my PC BGs 10-11 mmol/L (180-198 mg/dL)
- New GP
 - Referred to Ophthalmologist... all ok
 - Referred to another Endo Jan 06... BW, urine
 - Referred to another Endo May 06 Pituitary Specialist

Dx-Day... June 15, 2006

Inferior Petrosal Sinus SAMPLING:

(Levels of ACTH)

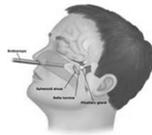
	Left	Right	Peripheral
Baseline	4	6	2
• Post CRH 2min	9	97	2
• Post CRH 5 min	15	92	3
• Post CRH 10 min	19	97	13



Diagnostic for Pituitary Microadenoma

Treatment Options

- Drugs to inhibit cortisol synthesis
ex) Ketoconazole, metyrapone
- Radiation of pituitary tumor
- Transphenoidal resection of the pituitary



Neurosurgery

- Endoscopic Transphenoidal Surgery Sep 19/06
 - DC'd Sept 22nd
 - Sept 27th SIADH readmitted DC'd Oct 1st
 - Cortisol remains 'high normal'
- Endoscopic Transphenoidal Surgery Feb 13/07
 - Admitted, IV running, CT done... surgery cancelled
- Endoscopic Transphenoidal Surgery Mar 9/07
 - DC'd Mar 13th, with DI, last ever period, CSF leak, low thyroid, Cortisol 1080...760... 365 on DC
 - Mar 15th cortisol 52... on replacement hydrocortisone

Post Surgery...



September 2006... and again in March 2007

However... not cured

- Elevated cortisol off hydrocortisone Nov 08
 - Started Ketoconazole Dec 08... flat out on couch 24 hours, rash on elbows, nausea, body aches, headaches, worsened eczema... stopped.
- Saw Naturopath (ND) re: elevated cortisol Jan 09
 - Started acupuncture, liver cleanse, cortisol lowering pill
- Endo refused to follow me along with ND Mar 09
 - Referred to another Endo who said "If you are taking something that is working, I need to know what it is and if it will help my other patients" testing of 'natural' pill

Serendipity

- Bad headache first week of March
 - Not relieved by medications
- Follow up MRI Mar 08
 - Reveals transverse sinus venous blood clot
 - Urgent referral to Neurology... on Coumadin
- Neuro follow up July 08
 - Whooshing in head when lying on my right side.
 - "Oh it is probably just revascularization. Don't worry about it."

Am I Crazy?

- Called Neurologist Aug 08
 - Pulsatile tinnitus, vertigo, head rush “You are due for a follow up MRI in October, so we will just wait until then.”
- Symptoms continue to worsen Sept 08
 - Black out in kitchen, take myself to ER
 - Resident tells me “We did some tests and there is nothing wrong”

No I'm not Crazy

- Neurology follow up Dec 19/08
 - Told to start aspirin 2 weeks prior to visit... hives
 - 2.5 hours waiting in waiting room
 - “Are you depressed?” “Are you in denial?”
 - Has a listen to my pulsatile tinnitus
 - “That sounds like a huge AV fistula. Can I get my 2 residents to come and listen?”
- Jan 13th, 27th, Feb 3rd, finally Feb 10th... angiogram
 - “hmmm, not good veins huh?” nurse starting the IV
 - “I'm really good at what I do and you are all fixed. That was the biggest AV fistula I have ever seen.”
Neuroradiologist

Definition of Cushing's Disease

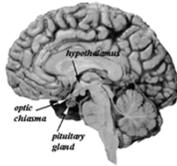
Cushing's Disease, described by Dr. Harvey William Cushing in 1932, is an endocrine disorder resulting from hypersecretion of glucocorticoids from the adrenal cortex secondary to hypersecretion of adrenocorticotrophic hormone (ACTH) from the pituitary gland. Cushing's disease is a form of Cushing syndrome which occurs when the body is exposed to high levels of cortisol.



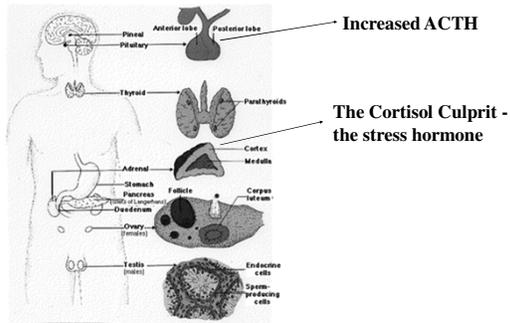
Basic Endocrine Anatomy & Physiology

Causes - tumor of the adrenal gland (rarely lung or abdomen)

- tumor of the anterior pituitary gland (My case)
- large doses of steroid medications (ie) prednisone



Basic A & P cont'd...

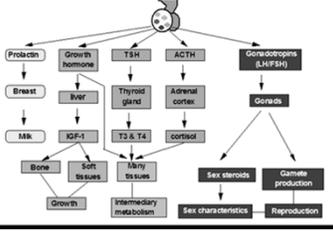


Signs & Symptoms of Cushing's Disease

- Fat deposits middle and upper back
- Thin skin, bruise easily, acne, plethora, pink/purple stretch marks
- Cuts, scratches and insect bites take a long time to heal
- Face may become round and puffy
- Feel tired and have weak muscles
- Depression
- Irregular menstrual periods, Hirsutism
- High blood pressure
- blood sugar levels that are higher than normal
- Increase prevalence of kidney stones
- Osteoporosis (only one I didn't have)

Post Surgery Issues:

Overview of anterior pituitary hormone functions



- Diabetes Insipidus: (lack of ADH from pituitary)
- No menses since March 2007
- GH-low
- TSH-low
- Cortisol- low
- CSF leak patched with my tummy fat
- Nasal hole patched with bovine pericardium
- Blood clot in sigmoid sinus of brain
- AV fistula

Rx and supplements



- Effexor 75 mg
- Synthroid 112 mcg
- Hydrocortisone 10 mg am, 5 mg pm
- DDAVP (desmopressin) 0.1 mg po BID
- Growth Hormone 0.25 mg SC daily
- Solu-Cortef 100 mg IM prn
- Calcium 600 mg
- Vit D 2000 IU
- Vit C extended 1000 mg
- Omega-3 900 mg
- Multivitamin
- Probiotic

What Happened to Work?

- Diabetes Camp
- Contract Insulin Pump/CGM training
- Adult Diabetes Clinic
- Pediatric Diabetes Clinic
- Endocrine Clinic