SECONDARY ADRENAL INSUFFICIENCY COMPILATION

(Created 12/19/17)

The following items were either printed in various NADF News® issues over the past nine years, or they are questions that NADF Medical Director Paul Margulies, MD, FACE, FACP has answered, but that have yet to be printed in the News®:

From NADF News®, VOL. XXII, No. 3 • 2007:

Q. Dear Dr. M, I was diagnosed with secondary pituitary adrenal insufficiency in 2000 after being treated with high doses of prednisone for sudden adult onset asthma. I went to Philadelphia this summer for a second opinion, as my endocrinologist is a very optimistic person and says he can get me off the steroids. He orders blood work every 6-8 weeks and gets a serum 8 a.m. cortisol level. Mine has been under 1 for most of the 9 years. The other endocrinologist ran the ACTH test. I take 7.5 mg of prednisone and he changed me to dexamethone for 5 days for the tests. The results came back as: Beginning cortisol level .4 - after an hour 3.9 - ACTH was <2. He concluded...1. I had Addison's. 2. I will be steroid dependent for the rest of my life. Do you agree? I want to stop weaning. I have been down to 6 mg of Prednisone a day and .2 of Florinef and felt half decent. The second opinion said my adrenals are shot and weaning now is not an option. Thank you for your time.

A. You do appear to have secondary adrenal insufficiency. The term Addison's disease is reserved for primary adrenal insufficiency, so do not use that term. Since you are unable to taper off steroids over the past 7 years, and the ACTH stimulation test shows an inadequate reserve, I would agree that you should stop trying to taper. It is interesting that you are on Florinef. Most people with secondary adrenal insufficiency have adequate aldosterone production and need only prednisone. If your pattern included a high potassium level and/or low blood pressure, then you would need to stay on the Florinef.

From NADF News®, VOL. XXIII, No. 3 • 2008:

Q. I have secondary adrenal insufficiency due to a depletion of ACTH. Should I take Cortef or Prednisone and in what amounts? I am a 5’1” tall 49-year-old female. I was put on Cortef two years ago because of subcutaneous inflammations and was told the Prednisone thins the layers of skin. Is this true. I've been taking 15 mg in the morning and 5 mg in the afternoon. I have been gaining weight on this med to the tune of 1/2 pound a month, steadily gaining 20 pounds. Any ideas as to what I should do?

A. Most people with secondary adrenal insufficiency have normal mineralcorticoid production (aldosterone) and lack only glucocorticoid production. Therefore, they can do very well with prednisone as their replacement steroid taken once every morning. Cortef has some mineralcorticoid activity which can raise blood pressure, and it is usually taken in 2 doses. Thinning of the skin, bruising, stretch marks and “Cushingoid” weight gain are due to the total dosage of the glucocorticoid, not the preparation. So, if you need the blood pressure assistance or potassium suppression from the Cortef, you can stay on it, but you may consider a smaller dose. Or, you can switch to prednisone and try a dose of 3 or 4 mg per day. All of these choices must be discussed with your own doctor.

Q. Why is it that when I am in a stressed situation that has caused sleeplessness, I can take cortisol and it puts me to sleep within 30 minutes? Is this normal? Also, trying to cut back on asthma inhaler Symbicort 160/4.5 which I think has led to nasal blockage (similar to a cold without congestion) and problems sleeping and tiredness. My allergist has no idea how to address my Addisons....I have secondary Addison's from chemo. Hope you can help me figure this out.

A. There are two questions here. Stress leading to sleeplessness would tend to require extra glucocorticoid therapy to handle the stress. I presume when the extra dose is taken, it helps to relieve the stress symptoms and adds to a more relaxed state. It does not cause the sleep directly. The use of steroid containing inhalers for asthma in the setting of secondary adrenal insufficiency can be tricky. As long as the usual baseline dose of glucocorticoid is sufficient and was not reduced when the inhaler was added, tapering slowly from the inhaler...
should not present much of an adrenal insufficiency effect. I would be more concerned about a return of asthma symptoms.

From NADF News® VOL. XXV, No. 3 & 4 • 2010

Q. In January 2010 I had surgery for Lichen Sclerosus (autoimmune). I was increased on my high potency topical steroids for about 3 months prior to surgery, then told I needed to stop after surgery to heal. I crashed. 3 different specialist have said in conversation (not diagnosis) that I have Addisons disease, after telling what happened. I have felt this is true since 2006 after a different surgery. Since I cannot seem to get referred to an endocrinologist, I have used Dessicated Adrenal for 2 years now. I had also tried stopping the dessicated adrenal when they told me no steroids after the surgery. That also contributed to my crashing (severe muscle weakness, salt cravings, extreme fatigue, vomiting, confusion) My question is, does anyone know if this supplement can give false normal cortisol levels, as it has some steroidal effects. I do know I cannot function without it. I am afraid when I finally have my endo appointment in Feb. that my levels may be false normals, and I will not get proper treatment. I also take Rehmannia periodically, as it has an immune suppressing activity to it. Thank you.

A. “Over the counter dessicated adrenal extract is unregulated. The FDA has inadequate resources to monitor ingredients. It is not legally allowed to have any significant hormonal activity, but who knows? I do not recommend it for anyone at anytime.”

From NADF News® VOL. XXVI, No. 2 • 2011

Q. “I was diagnosed with secondary adrenal insufficiency in Dec. of 1992 and have done very well on the hydrocortisone. My usual dosage is 20 mg in the am and 10 mg in the pm. I am also hypopit and take 100 mcg of levoxyl daily. This was all due to removal of a pituitary microandemona in July of 81 through an infertility workup. Fast forward to last Nov when I was diagnosed with stage 4 lung cancer (and never smoked). I have been given 14 whole brain radiations and one radio surgery to the brain. It has spread to the brain and liver. I was on Tarceva for a little over month, but had steadily felt weakened, wobbly legs, almost passed out 2 or 3 times, (actually I did pass out once but then realized I also had a bladder infection), short of breath, etc. I was taken off Tarceva a week ago and feel better, but also saw my endocrinologist last Friday & I was taking too much thyroid, thus the reduction to 100 mcg every day (it used to be 4 days a week at that level & 3 days at 112 mcg). My endocrine doc has never treated a cancer patient. And we trying to find the best dosage for the hydrocortisone. Do you have any thoughts on this? I know it is complicated and you have never met me, but I would appreciate your input. Thank you for all you do for NADF.”

A. “Although I cannot give specific recommendations about your care, I can suggest that you and your endocrinologist try to adjust the hydrocortisone dose according to your symptoms, just as you did before the cancer. This can be tricky, however, because the Tarceva itself can cause symptoms that resemble adrenal insufficiency, including fatigue, nausea, weakness and diarrhea. Since these symptoms can respond to additional doses of hydrocortisone, be aggressive about using it, raising the dose by 10 or 20 mg as needed. One other resource you have is the oncologist. Although your endocrinologist may not have experience with cancer, your oncologist does have experience with steroids, so communicate with both doctors.

From NADF News® VOL. XXVII, No. 1 • 2012

Q. My endo once told me that some people can’t tolerate prednisone or they don’t process it right...is that true?

A. Although fairly rare, some people lack the enzyme that converts prednisone to the active form, prednisolone. These people can use prednisolone instead of prednisone. Prednisolone is actually the preferred preparation in the UK, where prednisone is not available.

Q. Can you give us some information on the interaction between prednisone (as well as other corticosteroids) and calcium (acid neutralizing agents)? How much AI patients be concerned?
A. The interaction of glucocorticoids and calcium has several facets. Many people take calcium antacids with their steroids because they think they need it to reduce the incidence of heartburn from the steroids. In fact, that is rarely needed. Glucocorticoids are known to cause calcium loss leading to osteoporosis, but research has shown that the replacement doses used to treat Addison’s disease do not increase that risk. I do recommend calcium supplements for postmenopausal Addisisonian women, but the dose is the same as other women. Vitamin D is important to assess in all postmenopausal women, and vitamin D supplementation to achieve blood levels above 30 is important. High doses of glucocorticoids may suppress vitamin D levels as well as activity, but normal replacement doses should not effect vitamin D.

From NADF News®, VOL. XXVII, No. 3 • 2012

Q. What is the most optimal form of cortisone and optimal dosing for a person who has cortisone induced Addison’s, or is it called another name because it was drug induced?

A. Steroid induced adrenal insufficiency is a form of secondary adrenal insufficiency and should not be called Addison’s disease. That name refers to primary adrenal insufficiency due to destruction of the adrenals. The major difference is the need for replacement of both glucocorticoid and mineralocorticoid hormones in Addison’s versus the need for only glucocorticoids in most people with secondary adrenal insufficiency. There is no perfect treatment dose. Each person needs individual monitoring. For secondary adrenal insufficiency, I would often start with prednisone 5 mg every morning and then adjust upward or downward as needed.

Not yet published:

Q. Dear Dr M. I have secondary pituitary adrenal gland insufficiency. My 8 am cortisol level is always .8 (range 4-22). My renin level is almost always normal this month it was 0.5 (normal upright sitting nonhypertensive is 0.65-5.0 ng/m l/h/ My endo said my adreanl gland must be done something with these numbers on the renin activity. Presently I am on 8 mg of pred and trying to wean down to my base dose of 6 mg.I am also on .2 mg of florinef and my potassium level was 3.4 mmol/L and I take 20 mcq a day and now my endo doubled it after the blood test. First, do you agree? Second, what is the relationship between cortisol l and renin activity levels. Thank you for your time and consideration.

A. The lab results mentioned, which were taken while on prednisone and florinef do not give any useful information about any residual glucocorticoid or mineralocorticoid function. The AM serum cortisol would be expected to be very low in secondary adrenal insufficiency. Most people with secondary adrenal insufficiency retain mineralocorticoid (aldosterone) production, and do not usually need fludrocortisone (florinef). However, some people do need it. The best clue is an elevated serum potassium and an elevated plasma renin. Since you are on florinef, I assume it was added for that reason. Once on florinef, the dose is adjusted to keep the blood pressure normal, as well as a normal potassium and renin. Since the dose of florinef 0.2 mg is bringing the potassium and renin down to a low level, the treatment is to reduce the dose of florinef, not increase the potassium intake.

"Part 1: I had severe cramps in my legs at night prior to my secondary adrenal insufficiency diagnosis. After my diagnosis and replacement medication the leg cramps stopped. I get them on rare occasions or when I have had food posioning. Thank you.

Part 2: Thank you for the reply. The cramping only happens in the right calf and NOT always with food poisoning or diarrhea. I drink 65 to 80 ounces of water a day; I’m 5’5’’ and 125 lbs. Just months prior to my diagnosis of adrenal insufficiency I urinated up to 5 times a night; my urine looked like water. After the confirmed diagnosis and the first week of starting on replacement steroids my urine frequency decreased to twice a night; now it is usually once to twice a night. My endocrinologist thought the cramping may be a low mg+ but it was in the normal range."

A. Part 1: Most likely the cramps are due to decreased blood volume that is improved by the use of replace-
ment steroids for the adrenal insufficiency. Anything that will contribute to a decrease in blood volume, such as vomiting or diarrhea from food poisoning will bring back these symptoms. Always try to stay well hydrated and take extra steroids when you are ill.

Part 2: If the cramping is only on one side, it might be useful to have a vascular consultation to see if there is any evidence of peripheral vascular disease.

Q. After being on high dose prednisone on and off for my asthma I was always able to get off slowly and my adrenals kicked in. In 2001 I was on very high doses for 6 months, my doctor took me off quickly and my adrenals were never able to recover. I was very sick I thought I had the Flu went to and endo doctor and they put me on cortef 30mg. It took several years and I was able to take 10mg for two years. Several people from the nadf support group warned me that it was dangerous going to low and they were right. But my endo went on about how I could get off. In January 2009 I went to 5mg I did not realize what was happening to me but I was so tired lost my appetite I could not get out of bed I could not even drink water my husband could barely wake me. My family doctor put me on IV Fluids and injections id Solu-Cortef 100mg I could not eat or swallow the pills. The endo agreed I needed to be on the injections I was on them for 6 to 8 weeks. March 2009 was when I had the crisis. I have not been the same since. Then I went to 30mg I went to another endo and she said I should never go below 30 to 25mg cortef I should not try to go down that I would kill myself. The medicine is killing my stomach, I am taking 22.5mg of cortef now. I am sixty years old. This is my question. The new endo does not do a 24 hr urine cortisol test she says I don't need that test, as long as my potassium and sodium is normal. The old endo did my 24 hr urine cortisol Free test every couple of months. I went back to him and had another 24hr urine and my 24hr urine cortisol free urine was 114.3. The normal range is 4.0-50.5 he said it was to high, But my cortisol in the blood serum cortisol was 1.3 and my ACTH Plasma is 5. he says I need to go down he was very sure and one day I could get off. I need to know which is accurate the cortisol in the blood serum or the 24hr urine cortisol free This is very scary and I don't feel well. I went back to the 2nd endo and showed her the 24hr blood test and she said my pituitary is not making ACTH its only 5 cortisol in the blood 1.3. Is the 24 hr urine cortisol free in the urine 114.3 high dangerous? she said it was not and you can't go by that. Also since I had this crisis I have been dizzy when I wake in the middle of the night to go to the bathroom I have to wait a little if I get up to quickly I get dizzy. Is this from the adrenal insufficiency? I'm sorry I think I have repeated myself several times I wish I could speak to you by phone I'm never good on the internet. I have spoke to Jan Judge several times and she thought you would be able to get some answers for me no one seems to know about cortisol in the urine and if it is dangerous and one doctor scarying me into going down. I don't know what dose to stay on.

A. It is difficult for me to interpret the test values because there may be other factors that may effect the tests other than her hydrocortisone - such as other medications and other medical conditions. I will say that I tend to side with the endocrinologist who does not do frequent testing of blood or urine cortisols. Once the decision has been made that the secondary adrenal insufficiency is permanant, the replacement dose is based on the clinical response, not the cortisol levels. If she is gaining weight, developing Cushinoid changes, having elevations in blood pressure or blood sugar or getting low levels of potassium, then the dose should be lowered. If there is weight loss, lack of appetite, low blood pressure, dizziness, nausea, and excessive fatigue, then there is a reason to try a slightly higher dose. Always keep in mind the possiblity of other coincident medical problems, such as hypothyroidism that might confuse the picture.

Q. I have had secondary pituitary adrenal insufficiency for the past 10 years. I have severe weakness in all extremities the left worse than the right. My base dose of steroid is 6.5 mg of prednisone. I have had bilateral hip replacements and other orthopedic problems. My left fibula will dislocate from no trauma. My ankle strength is Fair (3/5) and never seems to get any stronger. I was a physical therapist and was very active before my adrenal glands failed. I fall frequently. I cannot exercise heavily due to the addison's fatigue, severe asthma, and I am morbidly obese. Due to exacerbations from the asthma, I am on a roller coaster with the prednisone. Is it possible to increase of the strength through exercise taking a steroid for life? Thank you.

A. The array of medical problems present a challenge for you. The need for steroid replacement therapy itself does not prevent you from exercising and improving your strength. However, higher doses of steroids like pred-
Nisone can contribute to muscle weakness, so it is important to work with your doctor on finding the lowest dose that keeps you comfortable. The obesity is also a major issue. It exacerbates the arthritis and makes it harder to exercise. With less exercise, there is more weight gain. There is no magic formula, but try to reduce the dose of prednisone if possible, diet as well as you can, and try to find some form of exercise that will not cause further injury.

Q. I have a question for the doctor if he has time to answer: I am currently maintained on 7.5mg Prednisone once daily for secondary adrenal insufficiency. I wondered if measuring the blood cortisol level is useful to determine my correct dose of Prednisone. My dose seems to be adequate, but my morning blood cortisol was low, 3.2 ug/dL. I don't know if the blood cortisol level correlates to my Prednisone dose, or if Prednisone does not affect the blood cortisol level and is metabolized differently. Thank you,

A. There is no benefit in measuring cortisol values in anyone taking prednisone. Serum cortisol does not measure prednisone levels, and the production of cortisol by the adrenals will be suppressed by the prednisone. Once a decision is made to treat secondary adrenal insufficiency with prednisone, the dosage is based on the clinical response and side effects, such as weight, blood pressure, signs of steroid excess, and routine blood tests for electrolytes, glucose and blood count.

Q. I talked to a man today, who had an adrenal gland removed because of Cushing's Syndrome. They are working on weaning him of the prednisone/hydrocortisone, and waking up his remaining adrenal gland. The man recently had some blood work done, and his creatinine and bun were slightly out of wack... He wants to know what this could mean.

A. I can't tell you exactly what is happening. BUN and creatinine reflect kidney function. If they are elevated, it could be just from transient dehydration or it may mean that kidney function is abnormal. He must clarify the situation with his doctor.

Q. What are your thoughts on secondary adrenal insufficiency and its link to fibromyalgia? I suffer from both and I have some websites that link the two together. The change in weather or increase in activity wreaks havoc on my body, especially my breast bone, ribs and hips. Again thank you very kindly for your words of wisdom. It is greatly appreciated.

A. There really is no direct link between secondary adrenal insufficiency and fibromyalgia. Fibromyalgia is a somewhat vague disorder causing waxing and waning muscle and joint pain and stiffness. The diagnosis is considered after classic arthritis disorders like rheumatoid arthritis, lupus and polymyalgia rheumatica are ruled out. The treatment is antiinflammatory medications, pain medications and often antidepressant medications. Secondary adrenal insufficiency can be caused by pituitary or hypothalamic disease, but is most commonly caused by prolonged use of steroid medications for systemic diseases like asthma, inflammatory bowel disease, and of course rheumatoid arthritis, lupus and polymyalgia rheumatica. Obviously, when there is a persistent need for steroids in any of these situations, the may be overlap with the management of the original disease. Furthermore, if there is an exacerbation of fibromyalgia symptoms or any other inflammatory symptoms, an increase in the dosage of the maintenance steroid may be needed. That is the link.

Q. When receiving supraphysiological dosages of cortisol of any type (in this case dexamethasone) for a very extended period of time, does the complete adrenal gland atrophy, or just the cortisol producing cells?

A. Just the cortisol producing cells.

Q. I had recently been referred to Dr. Salvatori (he happens to be the first on your list attached here) and I'd like to give you the feedback that he was incredible, thorough, helpful, and will be further assisting in my case after more testing is done. One thing I did learn from him that I had not found elsewhere is the link between adrenal insufficiency and long-term use of narcotics/opiates (in my case, for severe chronic pain from multiple diseases). I think this explains much of why so many people with my rare underlying genetic condition are being diagnosed with Addison's or other adrenal insufficiency diseases. Do you know if any research that's
been done regarding this connection? Thank you again,

A. I'm still confused about her question. Is she asking about chronic pain as a cause of Addison's disease? If so, I do not support that idea. Pain is a stress that can affect the management of Addison's disease and opiates can affect the metabolism of replacement steroids, but pain does not cause the destruction of the adrenal glands.

Q. To clarify, I had been told by Dr. Salvatori at Johns Hopkins (an adrenal specialist) as well as several of my other providers, endocrinologist included, that long-term use of narcotics/opiates can lead to adrenal insufficiency. In my case, it appears this was not the cause and that I have autoimmune Addison's Disease (the Florinef had already helped somewhat before even starting the Cortef, although my AM cortisol is still almost undetectable when not taking steroids for about 12 hours prior to testing; other testing appears to have confirmed this diagnosis as well).

So the question is if long-term use of these pain medications for other diagnoses can eventually lead to adrenal insufficiency?

Along that same line, there appears to be a curious number of people diagnosed with Ehlers-Danlos Syndrome (all subtypes), some who have never been on long-term pain meds, who have adrenal insufficiency let alone confirmed Addison's Disease. Would you know of anything that would connect a defect in collagen to Addison's Disease and/or adrenal insufficiency? It actually seems that most people diagnosed with Ehlers-Danlos have been tested with low cortisol levels and also have a large number of other symptoms. I've noticed on various EDS boards a lot of discussion about adrenal issues/low cortisol and/or Addison's Disease specifically. Even my geneticist mentioned he has a number of Ehlers-Danlos Addison's patients, and most people with EDS know a good handful of others with EDS and Addison's. It seems unusual given how rare Addison's and EDS both seem to be.

Lastly, there also seems to be a high correlation of Addison's Disease and military service. Many of us had unusual vaccinations and/or other exposures. Some veterans are claiming their Addison's Disease as service-connected, especially for those who had symptoms begin in initial training (although I'd guess if those in the latter group may have had the disease and that the added stress of this training could have made it more evident). Do you know of any connection here that might make sense for those writing to me about their claims? Thanks so much,

A. A lot of unrelated musings here. I do not support the notion that use of pain medication causes Addison's disease. I can find no published article linking Ehlers-Danlos syndrome with Addison's disease. I found one paper from 1991 in the European literature suggesting a low cortisol and suggesting stress coverage with steroids, but they provided no evidence of primary adrenal disease, and this recommendation is not followed by doctors treating this syndrome. Finally, what evidence is there for a connection to military service? Let us all be careful about perpetuating anecdotal connections or theories about adrenal diseases. If there is any scientific publication about any of these theories, please pass them on to me. I am always happy to learn.

Q. Hello. I've been in touch with NADF since last summer, a few times....this seems like a rather long road. Hoping to get some advice/direction. From what I've found with my own research, my test results indicate adrenal insufficiency. The latest endocrinologist with the latest test says I'm fine. Here's what I've got:

Cortisol has measured:
0 - June '11
0 - November '11
8 - November '11
6 - January '12 (ER, was sick, vomiting, horrible explosive headache) - ER doctor wanted to start treating me but my endocrinologist said 'no,' wait for further testing. Potassium was also low. Follow-up check was supposed to be done by dr but never was...ER staff called for follow-up & was very unhappy over this.

DHEA:
0 - October ‘11 (OB/GYN said he had never seen a level like that in his career)

ACTH:
less than 5 - November '11
10 - November '11

ACTH Stimulation Test: (this test has actually been done FOUR times, two times done wrong, fourth time they lost the results & took a month to get back with me)
16.3, 16.5, 16.2 - February '12 (they didn't trust these results, investigated Quest & insisted on doing again, despite determining test & lab work done correctly)
8.3, 16.7, 17.6 - April '12 (received these results yesterday)

They called yesterday & left message stating results were fine, I called back to get the actual numbers. The nurse gave them to me, stating that each was low as she gave them to me. I told her I agreed but that the resident who left the message had said they were fine & that the attending agreed. I spoke w/ my rheumatologist and found out that the new endocrinologist had been his professor, thus, doubtful he would question his interpretation of the results. I went outside & had a good long cry. Don't know what to do.

My original endocrinologist referred me to the current because she was in unfamiliar territory. My OB/GYN referred me to the original endocrinologist because that is not his area. And, as noted, my rheumatologist studied under the new endocrinologist, who is a professor at Wash U.

Are you able to tell me if these results are normal/okay or indicative of adrenal insufficiency? And, any suggestions of what the flip to do at this point? I feel defeated. I can't even get through the grocery store...I quit. It's exhausting and painful. I have muscle weakness/fatigue, joint pain, abdominal pain, headaches, general fatigue/lack of function. I desperately need answers to get my life back. I don't want to have adrenal insufficiency but, given that I clearly have a problem(s), at this point, I want an answer(s). I feel like I'm losing it.

I appreciate any feedback you can provide.

Regards,

A. "Lab results by themselves can be misleading. The full clinical context - history, physical exam, medication history, and other basic lab results are all critical in making a diagnosis of adrenal insufficiency. Therefore, although I cannot give you a definitive answer, the latest results show a normal response to ACTH and are not diagnostic of adrenal insufficiency. If other aspects of your history point toward Addison's disease, I suggest that your doctor add 21OH antibodies to test for autoimmune Addison's. If your history is more suggestive of secondary adrenal insufficiency, this test is not useful."

Q. "...have you ever experienced or heard of pseudotumor cerebri with patients taking Cortef / Hydrocort who have adrenal disease? Looking for some quality information on this topic or quality sites to check out on this topic."

A. Pseudotumor cerebri is a fairly rare disorder in which the intracranial pressure increases but the brain is otherwise normal. It usually presents with a change in vision. Most of the time there is no specific cause, but is has been reported in association with adrenal disorders. The most common link is with recovery from Cushings disease (after surgery) when hydrocortisone is being tapered. It has been seen with steroid tapers from other forms of relative secondary adrenal insufficiency. And, it has rarely been seen at the onset of Addison's disease. Generally, stabilization of the hydrocortisone dosage has helped and often cured it.

Other mentions of secondary adrenal insufficiency from the NADF News®:

From NADF News® VOL. XXV, No. 3 & 4 • 2010
“Interesting story to share ~ 3 to 4 times a year, for 3 to 4 years, my husband was receiving steroid injections in his back for degenerative disc disease. After hip replacement surgery, he developed a blood clot in his leg and the pain management doctor stopped the steroid injections while my husband was on blood thinner. He developed the symptoms of adrenal insufficiency a few months later and visited the first endocrinologist in June 2009. This doctor diagnosed my husband with Addison’s Disease. He was put on 30 mg hydrocortisone, fludrocortisone acetate, and testosterone. He had bloodwork and went back to the doctor every three months, but still never felt well. Anytime he would tell the doctor he wasn’t feeling well, he was told to ‘double-up’ on the hydrocortisone. He had not gotten any relief and the steroids were having horrible side effects. We finally went to an endocrinologist at Johns Hopkins for a second opinion. (Actually saw two doctors there - one doing her fellowship). The doctors reviewed all of the bloodwork done by the first doctor - they said that my husband had secondary adrenal insufficiency from supra-physiological medicating with cortisol injections, not Addison’s, and that his adrenal glands could possibly start working again. They said he should have only been on 15 mg of hydrocortisone and did not need the other two steroids. What a relief! We felt like a ton of bricks had been lifted off of our shoulders. The steroids were probably making him sicker. I just hope that they didn’t do too much damage. I wanted to share this story.” G. H.

From NADF News®, VOL. XXIV, No. 4 • 2009

KUDOS TO NADF’S WONDERFUL VOLUNTEER FELLOWSHIP GROUP PERSONNEL

From Florida member Caren Magne on November 24, 2009

“Hello Everyone from NADF! Since this is a time to be thankful I wanted to extend my thanks to everyone who has contacted me and helped me thru this secondary induced Addison’s disease that my daughter Claudia had for a year. I especially want to thank Dawn who without her support and help and talking to me and my husband (who at first didn’t believe that Addison’s was serious) on the phone I don’t think we could have dealt with this. My daughter’s adrenal glands started working again and her cortisol is near normal again as per her last bloodwork!!! My heart goes out to all of you and for all your support and help. Thank you and have a wonderful Thanksgiving. Caren Magne mother of Claudia 7 years old.”

Caren Magne also wrote to Jacksonville, Florida fellowship group founder/leader/facilitator Linda Munnell on Nov 25, 2009

“Dear LINDA! I just want to thank you so much for helping me thru this mentally and by warning me about what I needed to look out for. Without your help I don’t think Claudia would be as healthy as she is. Thank you again. Caren Magne mother of Claudia 7 years old.”

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is a non-profit organization providing information, education
and support to all persons affected by adrenal disease.

For more information on joining NADF,
or to find a support group in your area, contact:

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