

NATIONAL ADRENAL DISEASES FOUNDATION

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NADF

Education is the Key!
News[®]

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President's Corner



Dear NADF Members,
Happy back-to-school season! As a reminder, if your child is adrenal insufficient, please make sure you visit the school's administrative staff. Let them know about your child's condition and the special treatment that is required during emergencies. I encourage you to visit our web site <http://www.nadf.us/tools-for-life/> and print the handouts Adrenal Crisis Alert Poster and Endocrine Society Clinical Practice Guidelines. Also, please make sure to update any and all emergency contact information.

A note to support group leaders: We've received positive feedback from you regarding our periodic conference calls. By hosting these meetings we aim to improve communication and coordination between support groups. To that end, we will begin scheduling the calls quarterly. Please check your emails, and look for a calendar invite. We hope you will join us.

Whether or not you are a member of a local support group, I encourage you to visit the Addison's Disease Support Group on Facebook. You may be eligible to receive 20% off of Road ID medical bracelets. The ADSG will purchase IDs for those who truly cannot afford them. In addition, the group's founder, Lisa Markland, will be publishing a compilation of Addisonians stories. All proceeds will be donated to NADF (Thank you Lisa!).

*Another book I hope you will take a look at is *The Beautiful Disease: A Story About Addison*. The book's author is Judy Coppock. In this autobiography, Judy reveals her wonderful sense of humor and shows us how she learned to manage work, family, and Addison's. \$1.00 from every book sold is donated to NADF (Thank you Judy!).*

Thank you to all NADF members for your on-going support. Remember, no matter how small your contribution, it is priceless to NADF and all adrenal patients.

Regards,
Kalina

Flu-Season is on its way!
NADF reminds our readers the importance of staying up to date with a yearly flu-vaccination.

Potential Cause of Cushing Syndrome Found

Researchers at the National Institute of Health (NIH) have conducted a study which suggests mutations in the gene CABLES1 may lead to Cushing syndrome. The researchers collaborated with other institutions in the US, France, and Canada by scanning tumor and cell tissue from 146 children with pituitary tumors evaluated for Cushing syndrome. Additionally, 35 adult patients with Cushing syndrome and pituitary tumors were also studied in France.

Mutated forms of the CABLES1 gene were found in four patients to not respond to the presence of cortisol. Normally, the protein associated with the CABLES1 gene slows the division and growth of pituitary cells that produce adrenocorticotropic

(ACTH). ACTH stimulates the adrenal glands to produce cortisol, which then triggers the pituitary to stop producing ACTH-producing cells. Growth cells that are unaffected by cortisol are thus more likely to become increasingly ACTH producing tumors.

The mutations discovered in the CABLES1 gene represented only a small number of the patients in the study, but is a notable discovery in itself. Other genes have been implicated in pituitary tumor growth, so potentially other gene mutations have similar effects that can lead to Cushing syndrome.

For the original article about the study, visit:
<https://tinyurl.com/yblml5q5>

Emergency Injection Storage Idea

NADF affiliated Oregon support group leader Debbie Cheney, recently offered some advice for our adrenal insufficient patients, which she herself received from Adrenal Insufficiency United (AIU). For those of you who have had trouble finding a convenient way to store your emergency injection of hydrocortisone, you may want to try using a tall prescription bottle. Prescription bottles, or vials, are often durable plastic containers, offering water resistant and potentially child resistant storage for injections. Some are large enough to fit an entire kit including: the syringe, medicine vial, alcohol wipes, and perhaps other helpful things like salt supplements. Labeling them, and even decorating them with appropriate images, can help other people find them when necessary.

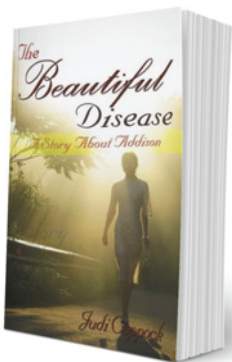
Debbie was able to procure a large amount of these bottles at no charge from her local Walgreens, and is planning to pass them out at a support group meeting. Your local pharmacy may be willing to simply give you an unused clean bottle for the purposes of storing your emergency injections, but they are also readily available and affordable on various online shopping sites, including Amazon.com. To have a bottle large enough for the entire injection kit, a “60 dram” bottle might be necessary. It is important to measure your needed tools, such as the syringe and vial, to see if they will fit in any container.

For a reminder of NADF’s instructions on emergency injections, visit www.nadf.us/tools-for-life/ and look under “Emergency Handouts.”



The Beautiful Disease

NADF is pleased to announce the release of the book *The Beautiful Disease* by long-time friend of NADF, Judi Coppock. Judi was diagnosed with Addison’s disease in 2001. She and her husband have struggled to get proper treatment for her rare condition. Through her experience she realized how others with the same condition as her have been largely ignored and even dismissed by some people in the medical community. She wrote her book to help raise awareness of Addison’s disease, and the way it affects the people it touches.



Judi is also helping support adrenal disease patients in her area by working with EMS in De Moines, Iowa. She met with 85 of their employees to help educate them about the specifics of Addisonians in a crisis situation.

We cannot thank Judi enough for her work in helping to raise awareness of

Adrenal disease. She is helping NADF raise funds with the sale of her book as well. Visit www.judicoppock.com to learn more and purchase her book, *THE BEAUTIFUL DISEASE*. If you enter “NADF” as the promotional code, \$1.00 from the sale of each book will be donated to NADF.

Great Non-Profits

If you love our work, then tell the world! Stories about us from people like you will help us make an even bigger impact in our community. GreatNonprofits – the #1 source of nonprofit stories and feedback – is honoring highly regarded nonprofits with their 2017 Top-Rated List. Please help us raise visibility for our work by posting a brief story of your experience with us. All content will be visible to potential donors and volunteers. It’s easy and only takes 3 minutes! Go here to get started: <https://tinyurl.com/y8late4p>

The deadline for submissions is October 31st.

Thank you!

Medial Alert ID’s and Death Prevention

EVERY person diagnosed with adrenal insufficiency needs to be wearing a medical alert! If it’s not on you it can’t help speak for you, and if it looks too much like jewelry it may be missed. Medical alert bracelets and necklaces should at a minimum state you have AI and are corticosteroid-dependent, indicating you need emergency stress dose steroids.

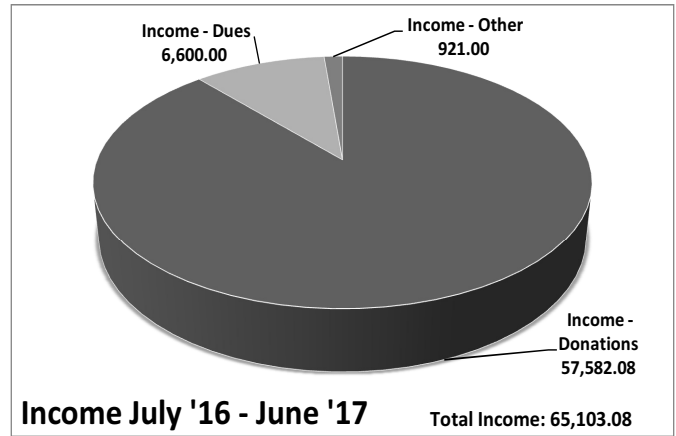
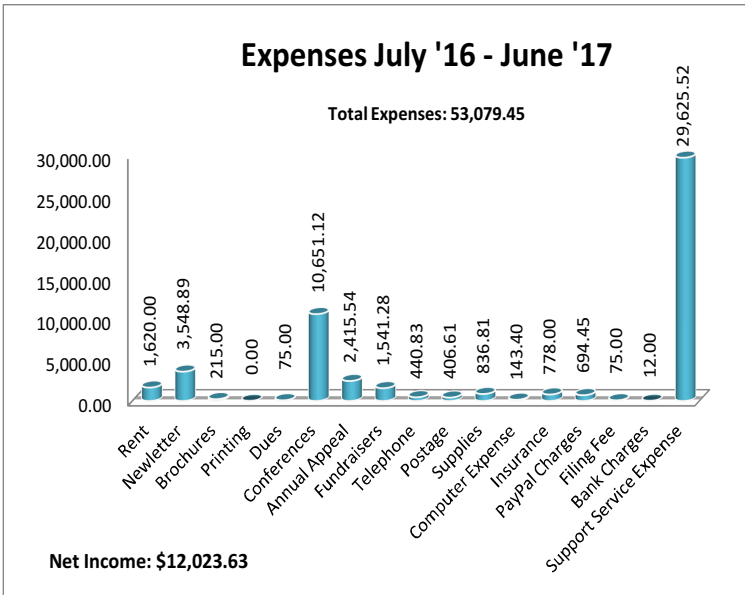
The Facebook based ADSG (Adrenal Diseases Support Group, previously the Addison’s Disease Support Group) will now have an ongoing 20% discount for all members of their group with diagnosed adrenal insufficiency, to make accessing a good quality medical alert easier and more affordable. For those with financial need, the group’s founder, Lisa J. Markland, can also provide any diagnosed member an extra \$10 gift card to use toward their purchase. If anyone truly cannot afford their own, the ADSG will buy this for them, asking the member to only cover the flat shipping fee of \$3 U.S. or \$5 internationally. The ADSG does not benefit whatsoever by offering this program, other than knowing they are helping to save lives by assuring nobody with AI is without a medical alert for financial reasons. These medical alerts are purchased through Road ID, a leading supplier of medical alerts, also having an Interactive program which provides live 24/7 secure, worldwide phone and internet support to your emergency profile (this is very much like traditional MedicAlert’s program for less money and is just as recognizable). We have seen these repeatedly save lives. If you have questions or need this assistance, contact the ADSG at www.facebook.com/groups/addisons.support.

Anyone can help donate to fund these lifesaving medical alert bracelets by visiting:

<https://www.facebook.com/ADSG.Fund>

This page also has information for any diagnosed person looking for a bracelet.

NADF Financials



Generosity Bestowed on NADF

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Advisors Capitol, Inc.

Advisors Capitol, Inc. makes donations to NADF on behalf of their clients. This was organized by Michael Beechie, and raised \$175 this year.

NADF would like to thank Brenda Bosse for helping arrange a Tupperware Party Fundraiser with Alabama support group leader Dana Baker, and Ashley Blake, raising \$215.00.

Conference on Adrenal Insufficiency

We wanted to make people aware of the Adrenal Insufficiency conference that Adrenal Insufficiency United (AIU) is hosting in Kansas City, MO, March 23 – 25, 2018. It will be their first stand-alone conference for adrenal insufficiency, and will include guest speakers.

At the conference, there will be sessions aimed at addressing the needs of affected adults and children. It will be held at the

Embassy Suites Kansas City Airport Hotel.

Registration for the conference will open in September or October of this year.

For more information on the event visit its Facebook page at: <https://tinyurl.com/y8xqrdra>

Contact information for AIU can be found at: <https://aiunited.org/>

Patients' Rights

We would like to help make our reader's aware of their rights as patients. In the 1970's, the American Hospital Association (AHA) introduced a Patients' Bill of Rights, which was created to help guarantee a certain consistent level of care. Since then, the AHA has replaced this Bill of Rights with the Patient Care Partnership, which is meant to be more easily understood. The Patient Care Partnership details what rights a patient should expect, covered under some basic headings:

- High quality hospital care.
- A clean and safe environment.
- Involvement in your care.
- Protection of your privacy.
- Help when leaving the hospital.
- Help with your billing claims.

The AHA offers the Patient Care Partnership online for free in multiple languages, and can be found here: <http://tinyurl.com/h7eyjys>

Since 2010, a newer Patients' Bill of Rights was created with the Affordable Care Act; the rights detailed are designed to give protections to patients dealing with health insurance, and were retrieved from the American Cancer Society (ACS):

- Annual and lifetime dollar limits to coverage of essential benefits have been removed. (Essential benefits include doctor and specialist visits, home and hospice services, emergency services, hospitalization, preventive and wellness services, chronic disease management, laboratory services, prescription drugs, maternity and newborn care, pediatric services, mental health and substance use disorder services, and rehabilitative services and devices. Nonessential benefits include things like adult dental care.)
- People will be able to get health insurance in spite of preexisting medical conditions (medical problems they have before getting insurance).
- You have the right to an easy-to-understand summary of benefits and coverage.

- Young adults are able to stay on a parent's policy until age 26 if they meet certain requirements.
- You're entitled to certain preventive screening without paying extra fees or copays.
- If your plan denies payment for a medical treatment or service, you must be told why it was refused, and how to appeal (fight) that decision.
- You have the right to appeal the payment decisions of private health plans (called an "internal appeal"). You also have the right to a review by an independent organization (called an "outside review") if the company still doesn't want to pay.
- Larger insurance companies must spend 80% to 85% of their premiums on health care and improvement of care rather than on salaries, overhead, and marketing.
- If you made an honest mistake on your insurance application, health insurance companies will no longer be able to rescind (take back) your health coverage after you get sick. (They can still cancel coverage if you don't pay premiums on time, if you lied on your application form, or if they no longer offer plans in your region.)
- If a company does cancel your coverage, they must give you at least 30 days' notice.
- Premium increases of more than 10% must be explained and clearly justified.

The source of this information can be found here: <http://tinyurl.com/hoguvje>

Patients' rights may vary from state to state, and various organizations recognize different rights pertaining to specific issues. NADF recommends strongly that our readers be as familiar as possible with their rights as patients, and understand that the hospital care system is meant to serve them.

Further resources for understanding your rights as a patient can be found here: <https://medlineplus.gov/patientrights.html>

Action for Adrenal Awareness

Kim Burnette and the other members of Action for Adrenal Awareness on YouTube have been nominated for two We Go Health awards: best team performance and best in show YouTube. The Action for Adrenal Awareness team have been recognized for their efforts to bring raise awareness and shine a light on the struggles for adrenal patients and their supporters. You can help endorse their nomination and raise their online profile by visiting the following link and clicking the orange "Endorse" button: <https://awards.wegohealth.com/nominees/12872>

For their latest videos go to: <https://tinyurl.com/jxn48lc>

Shop Around For The Best Price When Buying Solu-Cortef®

Solu-Cortef® injections provide life-saving medicine to people with adrenal insufficiency during emergencies. Solu-Cortef® vials should be replaced occasionally, either after use or when the medication expires. (Have you checked the expiration date on your Solu-Cortef® lately?) When it's time to refill, it's a good idea to shop around, regardless of whether your insurance covers costs or not. Sales price can vary significantly between pharmacies. There may even be occasions where cash price is lower than insurance deductibles. To compare prices you can call around or use a search site, such as GoodRx.com, to compare prices. The average price range for Solu-Cortef® is currently \$12-18 per vial. If you find pharmacies charging more than \$54 or higher, we would like to hear from you. Please contact Alex Farrell at alexfarrell.nadf@gmail.com with the date of discovery or purchase, pharmacy name, and cost.

Q & A

By Paul Margulies, M.D., FACE, FACP



Q. I've been having trouble with levothyroxine lately. I think it's dosage by manufacturer differences. Anyway, what the official word on brand vs. generic for thyroid supplement? Is Synthroid thought to be preferable?

A. I like to use a brand and stay loyal to that brand for consistency. The generics are OK, but the pharmacist can switch to another generic without asking, and that can cause a slight change in the blood level. In addition to Synthroid, other good brands are Levoxyl, Unithroid, and a gel capsule called Tirosint.

Q. I'm traveling to Zika infested countries soon. Any special considerations for adrenal insufficiency patients?

A. Zika virus infection presents no special risk to people with adrenal insufficiency. Most get a mild brief illness, or no symptoms at all. The real issue is pregnancy. Pregnant women, those trying to conceive, and men who might contribute to a conception within the next 6 months should avoid areas of infestation.

Q. Can "disseminated histoplasmosis" cause adrenal insufficiency?

A. Yes, although quite rare, disseminated histoplasmosis has been reported to cause Addison's disease by destroying both adrenal glands.

MAILBOX



The following are excerpts from letters and emails sent in, and do not necessarily reflect the beliefs or goals of NADF.

[...]I am forever indebted to whomever created this website! (www.NADF.us) I desperately searched the web to help save my mother's life. I asked the doctor if it was possible that she had primary adrenal crisis because she was taken of of the prednisone 2 and a half weeks prior. The reply I received was a condescending and arrogant "No, she's just tired from being in the hospital too much. And her blood pressure would be low if she had it." Then I came across your website and found a diagnosis for my mother. "It literally saved her life!"[...] Please accept my undying gratitude for saving my mother's life! Thank you.

AmazonSmile

NADF would like to remind its readers about AmazonSmile, offered by Amazon.com. AmazonSmile allows people to raise money for their favorite causes, just by making the purchases they usually would online; at no extra cost! Just log in to your regular Amazon account through smile.Amazon.com and select the National Adrenal Diseases Foundation Inc. as your charity of choice!

Thank you for your generosity!

Websites of Interest

<https://cushingsbios.com/>

Cushing's Bios is a collection of personal stories from Cushing's patients, about diagnosis and living with the condition.

Q. I was diagnosed with Addison's Disease when I was 23 years old. I'm a female and have since gone on to have three healthy children and have led a very productive life. For the first 20 years, I was treated with Prednisone and Florinef. About 6 or so years ago, my doctor switched me to 15mg of Hydrocortisone a day, along with .1mg of the Florinef. I also take 50mg of Zoloft (which was prescribed to help deal with extra anxiety since I do not produce extra cortisone when I'm feeling stressed). I am now 49 years old and feel that I might be entering menopause - I have been having severe irritability, and anxiety and depression. It's like a cloud has descended over me and I actually feel the weight of it on my chest. I've always had short bouts of blueness but they never lasted very long and I think they have been related to my cycle however now the bouts of blueness and depression have settled in and aren't lifting. I am wondering if hormone changes will require additional help with my steroid usage?

A. Menopause itself does not necessarily require an adjustment in hydrocortisone dosage. However, I think it is time to discuss with your endocrinologist how you are feeling. Since all of the hydrocortisone is taken in the morning, it might be worthwhile considering a restructuring of the dosage to have some in the morning plus a little in the afternoon. Also, consider a change in the Zoloft - perhaps an increase in dose, or a change to something else. If the menstrual cycle has stopped and there are significant flushes and night sweats that disturb sleep, consider adding a low dose of hormone replacement therapy if there is no contraindication. This may help with sleep, energy and mood.

Medtronic Pump used for Hydrocortisone

Connie Barczak, an NADF member, shared her personal story of using the Medtronic pump to administer her doses of Solu-Cortef®:

I have had Addison's for 8yrs. my endocrinologist put me on Solu-Cortef® about 3yrs. ago. I administer it by using a Medtronic pump. The results have been excellent. Every two days I add the Solu-Cortef® after I mixed the formula put into the pump (it is like an insulin pump.) The doctor regulated the amount and times I need a dose. I have had very good results and my cortisol levels have been perfect. I hope you can pass this on it does help with feeling tired and having to worry about my blood sugars going high when I took the pills.

While Connie's experience with using a pump to administer her medication for adrenal insufficiency has been positive, the FDA has not yet approved the pump for this purpose. As such, the Medtronic pump may not be covered by some forms of insurance for use as treatment for adrenal disease. We can only hope that will change soon!

Adrenal Gland Responsiveness

Research at the University of Bristol, in collaboration with the University of Exeter, have developed a novel mathematical model for the molecular network controlling glucocorticoid synthesis. This model was used to predict adrenal responses to stress experimentally in rats.

This new study of adrenal glands shows how they dynamically react to stress in the body, and how sensitive they are to such stimuli. While emotional stress may be entirely contained to the brain, the new model suggests the adrenal glands react directly to stress such as inflammatory conditions like injury or major surgery. Before this, there was little evidence to suggest that anything but the brain was in charge of governing hormone levels. This new research suggests otherwise.

It's too early to tell how this information will help adrenal patients, but any new discovery giving insight into how the adrenal glands works can lead to further discoveries that would be impossible before.

For more information, visit: <https://tinyurl.com/y9tbw8v>

SUPPORT GROUP UPDATES

Each support group has contact information provided on the page titled "NADF SUPPORT GROUP CONTACTS". If a group does not have an update below, if you have any questions about an individual group's next meeting, or need directions, please contact the person(s) listed there.

California/San Diego: This support group held a meeting on Saturday August 26th, where the focus was on helping new members cope with prescriptions and lifestyle changes. Their next meeting is currently scheduled for September 28th.

Michigan: This support group reported a very successful meeting on July 22nd, with 5 members and 4 support persons attending. The topics of discussion included diagnosis, current medications/therapies, sharing experiences and symptoms, review of emergency procedures, and review of NADF's educational literature. They are also discussing how to enhance and grow the group to further assist themselves and others with adrenal disease in their area. Their next meeting is scheduled for October 14th, from 10:00 AM – 12:00 PM local time.

New Jersey/South/SE Pennsylvania: This support group is planning on having their next meeting in October of this year. Details are being worked out.

Ohio: This support group's next meeting will be at the Blue Ash Public Library in Cincinnati, OH, on September 23rd from 1:00 PM – 3:00 PM EDT.

Texas/Houston: This support group met in early August with five people attending. Two of those people were parents to a teenage son with Addison's. They found the support group and supplied literature on Addison's extremely helpful.

Washington State: This support group held a meeting on June 24th, 2017. Their next meeting will be on October 21st, 2017 at Kent Commons in Kent, WA, from 10:00 AM – 12:00 PM.

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New Jersey/South/ SE Pennsylvania:	Jan Judge (856) 354-6029; janjpt@comcast.net	Kids' Pen Pal E-mail Network (NKPPEN)	If your child would like to sign on, please contact NADF headquarters at NADFMail@nadf.us
New York City:	Lori Wagner (212) 861-5545; lbwagner3@gmail.com	AI Medical Doctor Fellowship Group:	If you are a medical doctor with adrenal insufficiency, and would like to sign on, please contact headquarters at NADFMail@nadf.us
Ohio:	Susie Mathis (513) 290-5025; nadcincinnatigroup@gmail.com Carol Nantz (513) 861-8317; crrose1945@icloud.com	Young Adults E-mail List (ages 18-29):	If you are between the ages of 18 and 29, and would like to sign on, please contact NADF headquarters at NADFMail@nadf.us
Oklahoma:	Jessica Elzi; elzi.nadf@hotmail.com	Loved Ones of Adrenal Insufficient Patients List:	If you love an adrenal patient and would like to join, please contact NADF headquarters at NADFMail@nadf.us (Adrenal patients are excluded.)
Pennsylvania/ NE:	Holly Jagger (570) 289-6051; hjagger@echoes.net Catherine Yarmel (570) 851-1266; catdancing24@hotmail.com	Adrenal Insufficient Heroes List:	If you serve as a Police Officer, Firefighter or have another high stress life saving job and would like to join, please contact NADF headquarters at NADFMail@nadf.us
South Carolina:	Michele Gregory (864) 723-0075; chele8367@gmail.com	Parents/Guardians of Children with Adrenal Disease:	If you're the parent or legal guardian of a child with adrenal disease, and would like to join, please contact NADF headquarters at NADFMail@nadf.us

CONTACT YOUR GROUP ON FACEBOOK

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