NATIONAL ADRENAL DISEASES FOUNDATION QUARTERLY



NEWS®

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PRESIDENT'S CORNER

Dear NADF members,

April 2021 has been a very productive awareness

month. From creating new educational materials, to expanding our network of support groups, we can claim many successes. Significantly, we have received tremendous support from the American Association of Endocrine Surgeons (AAES), the Endocrine Society, and Hormone Health Network who partnered with us in many outreach activities and used social media to distribute information about adrenal diseases, diagnosis and treatment. A few examples include:

- An hour-long webinar created by AAES in celebration of Adrenal Awareness month. Guest speakers included: Dr. Quan-Yang Duh, Dr. Gary Hammer, Dr. Barbara Miller and Dr. Michael Corwin.
- A new educational webinar addressing adrenal insufficiency in children created by NADF in partnership with Dr. Geffner. Erin Foley, NADF VP, designed and moderated this webinar.

 A 10-minute Q&A video on Adrenal Disease and COVID-19 featuring Dr. Gary Hammer and our own Lori Engler, NADF Executive Director.

You will find links to all three videos which offer a wealth of information, on our website www.nadf.us/videos.

Also, Dr. Elizabeth Regan, our Board Member, participated in a panel discussion during the AAES annual meeting representing patient point of view.

In addition to establishing better collaboration with the medical community, we are also working on creating partnerships with other adrenal patient organizations. Please read more details on page 3 about the new Adrenal Patient Organization Consortium that was launched by NADF in February of this year.

With more and more people being immunized against COVID19 we are hoping that our lives will slowly start returning to normal. Please stay safe, visit the CDC website for information on latest science updates, guidance and safety tips

OVERVIEW

- President's Corner
- Education & Awareness
- Adrenal Insufficiency Research
- NADF Support Group Updates
- Q&A with Dr. Paul Margulies

To make a donation, please go here:
 www.nadf.us/donate.html.

You can also use the coupon on the bottom of page 8 to mail in your donation.

at: Coronavirus Disease 2019 (COVID-19) | CDC at www.cdc.gov/coronavirus/2019-nCoV/index.html. For additional information specific to adrenal patients, please refer to our website at: www.nadf.us/covid-19-information.html

Thank you for being an NADF member and for your ongoing support and generosity. Remember, no matter how small your contribution, it is priceless to NADF and all adrenal patients.

Regards, Kalina

June is CAH Awareness Month

See Facts You Need to Know: www.nadf.us/congenital-adrenal-hyperplasia-cah.html
Tildacerfont could be a new way to treat CAH. Learn more: https://www.nadf.us/cah-clinical-program.html

EDUCATION AND AWARENESS

An Addison's Disease Vintage Book Collection

By Holly Daugherty, NADF Support Group Leader



My collection began with an urge to find the history behind Addison's disease.

Being a history lover, a voracious reader and an Addisonian means that after my diagnosis the hunt for literature began. As expected, books published about adrenal disease are as rare as adrenal disease itself. Most of the books are several decades old but my collection is slowly growing. These are invaluable not

only for the information they contain - much of which I haven't found elsewhere - but also for their ability to show us how different life could be if we were living in an earlier era.

My collection began with an urge to find the history behind Addison's disease. I found my start in a reprint of a series of lectures given by Dr. Thomas Addison in 1875. Dr. Addison gives complete case histories of his patients including their names, ages and occupations. It was eerie to read the stories of these patients and to see my own experience mirrored so closely,

some describing signs and symptoms I had experienced myself but hadn't seen mentioned anywhere else.

Some of these books are dry and scientific: books on the adrenal gland in mammals, the adrenal cortex, and adrenal function in children. Two books from the 40s and 50s are transcripts of conversations between doctors and scientists discussing studies and experiments. The most fascinating so far is a book by American doctor George W. Thorn, a pioneer in adrenal insufficiency diagnosis and treatment. Published in 1949, it includes diagnostic methods and treatment guidelines. Most striking was a table listing the cost of hormone replacements. The financial burden imposed by treating adrenal insufficiency and frequent shortages meant that life expectancy was grim. After reading these books I came away with a sense of gratitude. We may have a long way to go with raising awareness and improvements to make with treatment options, but I can't help but feel grateful to be living today - in every possible sense.

If you'd like to learn more about Holly's book collection, you can email her at: hollydaughtery@gmail.com

Pediatric Adrenal Insufficiency (AI) Webinar



NADF provides valuable educational resources for pediatric AI parents and caretakers. If you haven't already seen it, tune into the webinar hosted by NADF and the esteemed pediatric endocrinologist, Dr. Mitchell Geffner. Here's the link for the Pediatric Adrenal Insufficiency

Webinar: https://www.youtube.com/watch?v=Uj3aCur0ae0

In addition to the webinar, NADF has added to the Children's section on our website with important awareness documents. To find these on NADF's website, you can go to Tools for Life, and find the Children's section or click here: https://www.nadf.us/ children-with-adrenal-insufficiency.html.

Hydrocortisone Granules Available for Pediatric Use

This new formulation offers the ability to

- accurately prescribe and administer smaller pediatricappropriate doses
- provide more flexible, individualized dosing with 4 lowstrength options as low as 0.5 mg
- · mask the bitter taste of hydrocortisone
- remove the need for pill manipulation, like cutting, splitting, and dissolving

You can find excellent patient resources here: www.alkindisprinkle.com/ patient/resources.



NADF Documents for **Children and Adults** Addison's Disease **HOWIN SPANISH!** Adrenal Crisis Alert Flyer for Children Emergency Injection **NADF** Alerta de Crisis Suprarrenal en Niños //www.nadf.us/ NADF

Spanish Version of Important Documents Available on **NADF's Website**

NADF has been adding the Spanish translations to important documents. As an example, the Adrenal Crisis Alert flyer, provides the signs, symptoms and Emergency Room treatment protocol for children in both English and Spanish.

Another important document offered in Spanish is the Emergency Kit for Adrenally Insufficient Patients, providing guidance on what should be included in the kit, including instructions and quick reference on how to inject Solu-Cortef.

You can find these and other important resources translated to Spanish in the TOOLS FOR LIFE section of our website. Just scroll down to TRANSLATIONS or use this link: https://www.nadf.us/translations.html.

EDUCATION AND AWARENESS continued

New Adrenal Patient Organization Consortium



We are excited to announce the launch of an Adrenal Patient Organization Consortium, created to work collaboratively with an international network of adrenal disease organizations who share a common bond: supporting adrenal disease communities. Organized by National Adrenal

Diseases Foundation (NADF) Executive Director Lori Engler, the

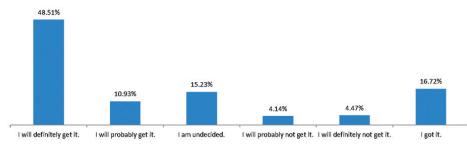
Consortium marks the historic alignment of efforts in the adrenal disease community with a focus on the following goals:

- Strengthening our ability to respond to important new information or crises affecting the adrenal disease community
- Creating a unified voice to improve awareness and education for patients, caregivers and the medical community
- Providing the best possible support to adrenal patients, caregivers and families through coordination across organizations

COVID-19 Update

NADF SURVEY ON COVID-19 VACCINE

See additional responses on the NADF website in this section: https://www.nadf.us/covid-19-vaccine-education.html



Most people indicate they will get the vaccine, but 23.8% of the surveyed population are not sure. This level continues to improve each month.

We continue to see that there is an opportunity to educate adrenal insufficiency patients on the importance of getting the COVID-19 vaccination.

Your survey feedback was used to create an Ask the Expert video, featuring Dr. Gary Hammer, Professor in the Departments of Internal Medicine (Metabolism, Endocrinology & Diabetes), Cell & Developmental Biology, and

Molecular & Integrative Physiology at the University of Michigan (UofM). He is also a past president of the Endocrine Society.





Questions about COVID-19 and adrenal insufficiency? Watch our latest #AskTheExpert video featuring @DrGaryHammer and @NADF's Lori Engler. #AADAM2021 https://bit.ly/3gKeKlt

ADRENAL DISEASE AND COVID-19

#AADAM2021





Severe COVID-19 Risks Greatly Increased for Children with Adrenal Insufficiency

COVID-19 infections put children at much higher risk for complications and death if they have either poorly controlled diabetes or adrenal insufficiency, according to two studies by researchers at the University of Arkansas for Medical Sciences (UAMS).

Read the full article: https://www.healio.com/news/ endocrinology/20210321/severe-covid19-risks-greatlyincreased-for-children-with-adrenal-insufficiency

NADF BOARD

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Susan Milliken – NADF Web and Communications Design Specialist Edward A. Wong – NADF Administrative Coordinator

VOLUNTEER

Pharmaceutical Company Liaison: Suzanne Bugbee

The NADF does not engage in the practice of medicine. It is not a medical authority, nor does it claim to have medical knowledge. In all cases, NADF recommends that you consult your own physician regarding any course of treatment or medication

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NADF's Participation in Medical Association Conferences Helps Build Awareness!

Many medical association conferences are increasingly placing attention on the patient point of view, and this is a great step for organizations like NADF. While many times patients and patient organizations have been involved passively in the past, now that dynamic is changing, and NADF is increasingly moving front

and center by playing more active role in a growing number of conferences – helping to build advocacy for those with adrenal disease. NADF is helping to increase education and awareness in the form of sharing important life-preserving information and participating in panel discussions with medical experts.

A Look Back at Adrenal Disease Awareness Month



APRIL IS ADRENAL DISEASE AWARENESS MONTH

NADF and other adrenal disease organizations really lit up the airways with incredible virtual programs throughout the month. NADF hosted

several programs, including a pediatric adrenal disease webinar, virtual walk, 'Ask the Expert' session, and much more. We want to personally thank our support group leaders and members for helping to spread awareness and making it a successful and memorable campaign.

To find more information or links to the recorded programs, please visit NADF's website at www.nadf.us, and look for videos or click here: https://www.nadf.us/videos.html

Many thanks to all of you for participating in these and other great events this April!



RESEARCH



Spark-PA Clinical Research Study for Primary **Aldosteronism**

Spark-PA is a clinical research study exploring an investigational study drug that may help people with primary aldosteronism (PA) lower their blood pressure.

Find out more: https://spark-pa.com/

Update from Dr John Porter, Medical Director, Diurnal

Diurnal is a European, UK-headquartered, specialty pharmaceutical company dedicated to developing medicines to improve lifelong treatment for rare and chronic endocrine conditions, including Congenital Adrenal Hyperplasia and Adrenal Insufficiency.

Diurnal's first product, Alkindi® Sprinkle, is a form of hydrocortisone specifically designed for young children. The product was approved by the Food and Drug Administration (FDA) last year and is now being made available in the US through Diurnal's partner Eton Pharmaceuticals.

Diurnal's current lead product in development is a novel modified-release formulation of hydrocortisone taken orally (development name Chronocort®). It is designed to match the normal rhythm of cortisol by replicating the overnight rise in cortisol and providing normal levels upon waking. Diurnal has been developing the medicine initially for CAH where it can help control excess levels of male hormone seen in that condition, but it is hoped that this overnight delivery will also improve the treatment of patients with other forms of adrenal failure.

RESEARCH continued

Diurnal recently published an international phase 3 clinical study of Chronocort® in patients with CAH in the Journal of Clinical Endocrinology and Metabolism. This Phase 3 study was conducted in a total of 122 patients enrolled across 11 clinical sites in the US and Europe, the largest ever interventional clinical trial completed in CAH patients. The paper also included results for longer term treatment with Chronocort over a further period of 18 months.

The full publication can be found at: https://academic.oup.com/ icem/article-lookup/doi/10.1210/clinem/dgab051

On the back of these results Diurnal has been able to take Chronocort through a licensing process in Europe and has recently received a positive opinion from the Committee for Human Medicinal Products of the European Medicines Agency. This means that Chronocort should be licensed in Europe within three months.

Diurnal hopes to follow up this license with licensing in Great Britain and have used the results of this study, in discussion with the FDA, to plan a pivotal US clinical study with Chronocort.

This study is planned to open at centers across the US later this year and will enroll up to 150 patients with classic CAH due to a deficiency of 21-hydroxylase. The study will be double blind, i.e., neither those taking part in the study or their doctors will know what treatment they are taking. Participants will be randomized to either Chronocort or hydrocortisone and will be on study for up to 15 months. At the end of the study participants can choose to continue into a follow-on study where all participants will receive Chronocort. More information regarding the study will follow soon and Diurnal will also be working with NADF to engage with the patient community to discuss the study and logistics so please watch this space.

Diurnal is also investigating the use of Chronocort for the treatment of Addison's disease with an early phase clinical study being run in Europe in 2021/2022. This will provide valuable information about the treatment of AI and support the design of a study to be run in the USA, estimated to start in 2023. Diurnal hopes to work with NADF to get patient feedback on the study design.

SUPPORT

NADF Support Group Updates WELCOME NEW SUPPORT GROUP LEADERS!



Courtney Coe Idaho Support Group Leader courtcoe@gmail.com

Courtney was diagnosed with Addison's Disease in 2016. She is married to a wonderfully supportive husband and has a 7-year-old daughter. Courtney lives in Boise, Idaho and works part time.



Lauren Meier Michigan Co-Support Group Leader

Lmeier677@gmail.com

Lauren was diagnosed with primary adrenal insufficiency at age 28 while getting a Masters in Nursing. Her adrenal disease inspires her to

continue to help others, and she is dedicated to being an advocate for patients with adrenal disease.



Joanne Power Maryland Support Group Leader Powerjo616@gmail.com

Joanne was diagnosed with Addison's disease and hypothyroidism at age 37. As a CPA, she works part time for a church and school and looks

forward to meeting everyone and sharing in their journey with adrenal disease.



Alicia Corbett Hawaii Support Group Leader acorbettjd@gmail.com

Alicia was diagnosed with Addison's disease in 2007. With lots of support from family, friends and doctors, Addison's disease didn't hold her

back from achieving her personal and professional dreams. She is looking forward to helping others get the information and support they need to live their best life with adrenal disease.



Andrea Turmelle Maine Support Group Leader

andreabethturmelle@gmail.com

Andrea has had hypothyroidism for 20 years, and was diagnosed with Addison's disease six years ago. She is a retired teacher and now spends time volunteering for her church and other local organizations.



Angie Bauer Arizona Support Group Leader moebowl88@gmail.com

Angie is currently a homemaker who dedicates her time caring for her children, including her 15-year-old son who was diagnosed with

Addison's disease in August 2020. She looks forward to supporting others and raising awareness in her community.



Rob and Judi O'Brien **Utah Support Group Leaders** Jobrien503@comcast.net

Rob & Judi's youngest daughter was diagnosed with Addison's Disease in 2016. It was a relief to know what had been causing so many of her

symptoms. They are excited to join more actively in the quest to bring about awareness of Adrenal Insufficiency as Utah's Support Group leaders.

If you would like to join a support group meeting but don't have a group in your local community, it's easy to join with virtual meetings! Just let our support group leader coordinator know and we'll get you set up. Email: nadfsupport@nadf.us.

Q & A BY PAUL MARGULIES, MD, FACE, FACP

O: Should individuals with adrenal insufficiency stress dose prior to receiving the COVID-19

A: I do not advise using extra glucocorticoids on the day before or on the day of vaccination. I suggest

the individual with adrenal insufficiency wait to see if significant side effects occur, usually the day after the vaccine. If there is fever, significant muscle aches and pains, and especially nausea or any typical adrenal insufficiency symptoms, I would then add stress dose steroids in addition to treating any fever with acetaminophen or ibuprofen.

I have spoken to many of my patients about their experiences, and many report no side effects at all. Those that did have significant symptoms were individuals who had a history of acute Covid-19 infection earlier in the year, and then had the vaccine.

Q: What if we've had both COVID-19 shots and want to travel? Thoughts? I also have Addison's Disease.

A: For the latest advice, look at: https://www.CDC.gov.

Q: I was on high-dose hydrocortisone, but stopped two months ago. I have heard it can weaken your immune system, so I'm wondering how long am I more susceptible to infections?

A: The answer depends on the clinical situation. If you have adrenal insufficiency it is dangerous to stop the glucocorticoids because the adrenal insufficiency must be treated. Fear of viral infections is never a reason to stop steroid therapy altogether. It is always essential to take the best dose that prevents adrenal insufficiency symptoms. Avoiding viral infections requires the use of the usual measures, including masks, hand washing and social distancing. However, if you are without adrenal insufficiency but required a short-term use of hydrocortisone and are now off it for 2 months, then sensitivity to viral infections is probably back to normal. Two months should be adequate.

Q: I have never seen any guidance on what to do if we have a severe allergic reaction (anaphylaxis) to something. My guess is that we would need both SoluCortef (or equivalent) and epinephrine. Would there be a problem if we were given only epinephrine without the SoluCortef?

A: The immediate treatment for anaphylaxis is epinephrine. If this were to occur in a person with adrenal insufficiency, I would recommend adding a stress dose of hydrocortisone 20 mg to cover the stress. IV or IM hydrocortisone would be appropriate only if there is a sustained allergic reaction after the use of epinephrine.

Q: I have primary adrenal insufficiency (PAI). Recently I was diagnosed with Valley Fever. What do you know about treating Valley Fever in people with PAI? Before the serology tests were known, my doctor mentioned the possibility of treating me with Fluconazole.

A: Valley Fever is a fungal infection caused by coccidioides. It is often quite mild and may resolve without treatment. In its severe form, it can cause pneumonia and sometimes meningitis. Severe Valley Fever is treated with antifungal medications, most often fluconazole. Adrenal insufficiency is a risk factor for more severe disease and its complications. Therefore, if the diagnosis is confirmed, treatment is likely to be advised. Unfortunately, the common side effects from fluconazole include nausea, dizziness, vomiting and diarrhea, all symptoms that occur in poorly controlled adrenal insufficiency. Clearly, treatment must be closely monitored. Extra doses of hydrocortisone may be necessary to cover the side effects of the medication.

Q: I'd like to start taking the minerals zinc and selenium daily; is this something that will disrupt my hydrocortisone or effect my Addison's Disease? If not, how much is appropriate?

A: Neither zinc nor selenium will have any effect on Addison's disease management. I do not specifically recommend either, but if you want to take them, there is no harm. Zinc is being promoted for anti-viral properties, but the benefit is minor. Selenium is promoted for autoimmune thyroid disease. I don't propose its use to patients because the studies showing a benefit were in people who lived in parts of the world with a deficiency of selenium. In the US, there really is no such deficiency.

Q: I have just been diagnosed with severe obstructive sleep apnea that affect my cortisol levels. Why do I have to keep updosing so much?

A: Obstructive sleep apnea can be a significant cause of daytime fatigue. It is usually treated with CPAP, a device that prevents the obstruction and allows adequate sleep. It is not treated with more glucocorticoids. In fact, excess steroids may cause weight gain that can worsen the sleep apnea. The key is to work with a sleep specialist on finding the best device to treat the sleep apnea, but use a normal replacement dose of glucocorticoids.

Q: I was recently diagnosed with an adenoma. Who is the best kind of specialist to see for adenomas?

A: Adrenal adenomas are quite common. The patient should be evaluated by an endocrinologist for adrenal function to determine if the adenoma is producing excess cortisol or any other adrenal hormone. The next issue is size and growth. Regardless of function, if the adenoma is bigger than 3.5 cm or is growing, surgical excision should be considered.

NADF Support Group Contacts

Alabama: Dana Baker; alabamaadrenaldz@gmail.com; (334) 332-8150

NEW Arizona/Phoenix: Kay Campbell; kcamp2468@aol.com; (602) 300-4336 OR

Co-Leader Angie Bauer; moebow188@gmail.com; (520) 366-2936

California/Orange County/LA: Karen (Ren) and Krystal Morey; socalspoonies@gmail.com; (949) 533-7101

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Florida/South; Sergio Mankita; sergiomankita@gmail.com; (786) 301-0005

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Lower Tier Upstate New York/NE PA: Holly Jagger; hjagger@echoes.net; (570) 289-6051

Contact your group on Facebook

NADF Young Adults: www.facebook.com/groups/293731041841451/ Alabama: www.facebook.com/groups/170299407129670/

Indiana, Kentucky and Ohio: www.facebook.com/NADFINKYOH/

Missouri/Kansas City: www.facebook.com/groups/2037889206442289

NJ/PA www.facebook.com/groups/382516102696032/

Oregon: www.facebook.com/nwaihelp

Southeastern www.facebook.com/groups/SoutheasternAdrenal/ Texas/Austin: <u>www.facebook.com/groups/CenTexADSupport/</u>

Texas/Corpus Christi: www.facebook.com/groups/CoastalBendNADF/

Texas/Houston: www.facebook.com/groups/426580274104281/ Texas/San Antonio: https://m.facebook.com/tanya.glaser.50 Washington State: www.facebook.com/groups/446690322114816/

Young Adults Facebook group: bit.ly/NADFYoungAdults

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Oklahoma: Holly Daugherty; hollyjdaugherty@gmail.com; (405) 361-1974

Oregon: Please check the group's Facebook page for upcoming

meetings: www.facebook.com/nwaihelp

Rocky Mountain: Sarah Reilley; rmadrenaldisease@gmail.com South Carolina/Coastal: Michele Torres; michelechs@live.com; (843) 324-5242

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Young Adults Group: Lesley Myrvold; l.myrvold@aol.com; bit.ly/NADFYoungAdults

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Pregnancy & Female Reproduction: Francesca Aquilino; francesca.aquilino@gmail.com; (832) 727-8567

Spanish Speaking Adrenal Patients and Advocates: Patricio Camacho; camacho.patricio09@gmail.com; (323) 919-7876

Cushings Specialty Support Group: Jennifer Shutte; jenschutte@gmail.com; (862) 219-9062

Internet/Inspire/Cushings: Jennifer Shutte; jenschutte@gmail.com; (862) 219-9062

We welcome others to join our other Specialty Support Groups. Please contact NADF Headquarters at NADF@nadfsupport.us.

Kids' Pen Pal E-mail Network (NKPPEN)

Young Adults E-mail List (ages 18-29): bit.ly/NADFYoungAdults

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NADF Inspire - Online Support Group Forum NADF Adrenal Insufficiency Support Community Cushing's Support Community

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THANK YOU FOR YOUR GIFT!

Thank you for thinking of National Adrenal Diseases Foundation (NADF)

We Want to Help...

We understand these are tough times. We want you to continue receiving the newsletter and staying informed of important adrenal

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Please make your check or money order out and send to:

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