

NATIONAL ADRENAL DISEASES FOUNDATION

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NADF

Education is the Key!
News[®]

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President's Corner



Dear NADF Members,

Within the last year, NADF has greatly expanded its outreach and awareness campaign to include the medical community. We attended the annual conferences of the Endocrine Society, American Association of Clinical Endocrinologists, American College of Emergency Physicians, and the American Academy of Family Physicians. These events

gave us an opportunity to talk with many healthcare professionals and to distribute countless pamphlets and fact sheets pertaining to the treatment of adrenal patients. We received very positive comments from many attendees and we are hoping to continue to participate in future meetings.

The Endocrine Society conference was also attended by NADF board member Elizabeth Regan, MD, Ph.D., who presented research results which were based on the NADF/ARNet survey. Also, we were happy to be a co-sponsor of our board member Lisa Martin's (MSN) presentation at the International Conference for Perianaesthesia Nurses. Her talk on Understanding Adrenal Insufficiency and its significance in the perioperative setting was attended by over 500 participants, and was a huge success.

As part of our awareness campaign, we have received and are distributing wallet-sized emergency cards from the Karolinska Institute in Sweden. If you receive hardcopies of our newsletters, please find one of these emergency cards affixed to this edition on page 5. If you receive NADF newsletters by email and wish to receive an emergency card, email your request to nadfmail@nadf.us; write "emergency card" in the subject line. The goal is to make these emergency cards internationally recognizable among first responders and healthcare professionals. Please fill out the card, and carry it on your person as a supplement to your medical bracelet, and the NADF emergency card.

Please note our new mailing address and phone number listed below. We updated our contact information to save NADF money while making correspondences more efficient.

The National Adrenal Diseases Foundation
P.O. Box 566
Lake Zurich, IL 60047
Phone: (847) 726-9010

Thank you for being our member. We at NADF sincerely hope you have a wonderful holiday season and a very happy New Year. Please take care of your health and stay strong.

Regards,
Kalina

Research Update

by Dr. Michael Huang, MD, CMO Spruce Biosciences

Spruce Biosciences, a biotechnology company developing novel therapies for rare endocrine disorders, is currently conducting a Phase 2 study to evaluate the safety and effectiveness of a new potential treatment in adults with classic congenital adrenal hyperplasia (CAH).

The investigational treatment, called SPR001, is a non-steroid, daily oral medication. SPR001 works through a different mechanism of action than the traditional steroids that are often used to treat CAH. SPR001 works at the level of the pituitary gland to reduce the abnormally high levels of adrenocorticotropic hormone (ACTH) and androgens seen in patients with CAH. By lowering hormones such as ACTH and androgens, SPR001 is designed to improve CAH symptoms and allow patients to reduce their daily intake of steroids.

Patients who qualify for the Phase 2 study will receive all study-related care and medication at no cost, and will be compensated for time and travel.

If the results of this initial Phase 2 study are promising, future clinical studies will be conducted with the eventual goal of providing patients and doctors with the first FDA-approved treatment specifically for CAH.

To qualify for the study, patients must be 18 years of age or older, have a diagnosis of classic CAH, and be currently taking a steroid for CAH (e.g., hydrocortisone, prednisone, dexamethasone, etc.). To learn more about this clinical trial or to complete a prescreen questionnaire to see if you are eligible, please visit www.CAHClinicalTrial.com or <https://clinicaltrials.gov/> and refer to study number: NCT03257462.

NADF Volunteer Achievements

Mary Case, Houston, TX support group facilitator, represented NADF at our booth at the AAFP Family Medicine Experience (FMX) this year. This was the first time we have ever presented at FMX, and was hoping to spread awareness among more general practitioners about adrenal insufficiency in all its forms. Luckily, despite the storms and hurricanes that battered Houston that September, Mary and the conference were not adversely affected at the event, and everything went according to schedule and plan.



Mary Case, Houston, TX support group facilitator.

We would like to highlight the efforts of some of our gracious volunteers as they represented NADF at various events this year, aimed at raising awareness and spreading information about adrenal disease.

In October, NADF made its second appearance at the Convention for the American College of Emergency Physicians (ACEP) in Washington, DC. Volunteers Dr. Joanne Vizzini and Ms. Rebecca Woodings stepped up to work our booth this year. Similar to last year, our goal was to spread awareness about the proper protocol for adrenal crisis, a condition that not all emergency response personnel are experienced with. Joanne and Rebecca were a great help dispensing our Adrenal Crisis Alert flyers to the ER doctors, EMTs, and other critical care providers.

Inez Wess represented NADF at the COA/Neal Senior Center Annual Health Fair in Shelby, NC. Inez contacted us with interest in participating in the local Senior Center Health Fair, where people can spread information about particular conditions, and promoting healthy living. Inez wanted to spread awareness and information about Addison's disease, and was looking for any educational material we could provide. Inez was nice enough to decorate her table with NADF's banner as she spread the word about Addison's disease.

NADF owes a huge debt of gratitude to our volunteers. By volunteering to represent NADF at events near their residence, it saves our precious resources in having to fly people out-of-state, and arrange accommodations at hotels. Their assistance is invaluable to us, and we thank them deeply.



Inez Wess.

Medical Alert ID's and Death Prevention

EVERY person diagnosed with adrenal insufficiency (AI) 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 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 ADSG can also provide any diagnosed member placing an order over \$20 an extra \$10 gift card to use toward their purchase. If any member truly

cannot afford their own, the ADSG will buy this entirely for them, shipping included, and can even cover any VAT/customs fees for overseas orders. 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, which also has an "Online Profile" 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 <https://www.facebook.com/ADSG.Fund/> using the "Message" button.

New Medication Updates

Treatment for adrenal insufficiency has not changed much for quite some time. Regardless of age, replacement steroid options are basically the same for everyone. Even though patients can have perfectly fulfilling lives on these medications, the adrenal insufficient community has needed better options. Progress, as it usually sadly is for orphan medications, has been slow.

One option that has been on the horizon for some time now is Chronocort®. Chronocort® is a form of extended-release hydrocortisone. Clinical trials regarding the efficacy of hormone replacement therapy for adrenal insufficiency suggest improvements can be made over traditional oral supplementation. Chronocort® is meant to do just that, by replicating physiological cortisol replacement. There are currently multiple clinical trials involving Chronocort®:

A Study of the Efficacy, Safety and Tolerability of Chronocort in Treating CAH (Recruiting as of 7/19/17):

<https://tinyurl.com/ybywrp6y>

Comparison of Chronocort® With Standard Glucocorticoid Therapy in Patients with Congenital Adrenal Hyperplasia (Recruiting as of 7/17/19):

<https://tinyurl.com/ydhlrrhd>

Study of Chronocort® Versus Cortef® in Healthy Adult Male Subjects (Not yet recruiting):

<https://tinyurl.com/ycoxae69>

Infacort® is another form of oral-hydrocortisone designed specifically for children under six years of age (possible approved for children 0-16 in the US); it is an immediate release form of hydrocortisone. Infacort® comes in smaller dosages than regular hydrocortisone; 0.5 mg, 1 mg, 2 mg, and 5 mg tablets. Before this, getting more incremental dosages of hydrocortisone by tablet required splitting whole tablets into smaller pieces, which can result in inaccurate dosing. Infacort® is aimed at offering much more accurate small dosages for adrenal insufficient youths, and has taste-masking excipients to help eliminate bitterness in taste so it's easier to get young children to take it. The clinical trial study is scheduled in the UK starting in December of this year. More information can be found here: <http://www.diurnal.co.uk/products-pipeline/infacort/>

Support Group Leaders Wanted

NADF is aided by a network of support group leaders and facilitators, who act as our contact to local adrenal patients in need. They are the backbone of our support network. Sadly, due to other commitments for their valuable time, support group leaders are not always available.

We are currently looking for people interested in leading a support group; either one that already exists or one they create, in the following areas:

Arkansas
San Francisco, CA
Los Angeles, CA
Ft. Lauderdale, FL
Miami, FL
Tampa Bay, FL
Iowa
Louisiana
Minnesota
Long Island, NY
Oklahoma
Utah

If interested and available, please send an email to NADFmail@nadf.us for inquiries about the requirements of the position.

Thank you.

GreatNonprofits 2017

NADF is proud to announce that we won a spot on the GreatNonprofits 2017 Top-Rated List! GreatNonprofits offers insight into non-profit organizations as a resource to the greater public, so people can make informed donations. Anyone who has had an experience with a non-profit organization can give their review and testimonial about it. Because reviews for NADF have been so positive, we were included in the Top Rated List.

We owe all of our supporters, volunteers, friends and family gratitude for helping us make the Top Rated list this year. We especially want to thank those of you who wrote such nice things about NADF on GreatNonprofits. Here are some of the reviews our supporters have written:

"NADF does a tireless job of educating the medical community of a disease that is classified as "rare" when it is increasingly becoming more common. I grateful for their support locally and Nationally. They do a great job!"

"NADF gives us tools and information that save lives. For the first time in my life, I was able to meet others with my disease (Isolated Central Adrenal Insufficiency), and to compare notes with them. We are even planning a research project together. Hopefully, our study will benefit many others with our disease. NADF has given to us without any profit motive what so ever. After a bad experience I had with a different pituitary disease organization/network, I am relieved to find people I can trust."

"I called NADF looking for a support group. While they didn't have one in my area, I immediately took on the role of Support Group Leader in my area. NADF sends out life-saving information. I am so much more knowledgeable about my disease since joining NADF, and I'm able to help others and support others. The Executive Director and the President of NADF are the most caring, compassionate, and trustworthy people you'll ever meet."

Your efforts increase our public profile, which in turns gives us better resources to reach out and help those affected by adrenal disease. We at NADF hope to live up to your expectations, and exceed them.

You can learn more, and write your own review at www.greatnonprofits.org. NADF's page there can be found at <https://greatnonprofits.org/org/the-national-adrenal-diseases-foundation-inc>.



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!

Rare Disease Databasing

For rare disease patients, it can be a struggle to find doctors who are aware of the special needs the patient requires. This is especially problematic in an emergency situation, such as when a rare disease patient is admitted to an Emergency Department (ED) from an acute condition, and must be treated by a doctor with no firsthand experience with the patient before. There is no guarantee that an emergency physician will be aware of any one person's unique situation, or that they will understand what special needs are required for every patient.

Adrenal insufficient patients, for example, have a special need others do not in an emergency situation. If in an ED, the patient will very likely need an emergency dosage of glucocorticoids. NADF has had repeated reports of AI patients not getting the steroids they needed when in hospital care, regardless of the department they were admitted to, as doctors and nurses don't necessarily understand how adrenal steroid replacement works. In the emergency room, this is particularly problematic as the patient may not even be conscious enough to be their own advocate for getting the steroids they need.

To deal with the issue of diagnosed patient records, some states have implemented shared databases designed to give physicians easy access to the information they need about the patients they see. In EDs, this is incredibly helpful. One example is the Emergency Department Information Exchange (EDIE), endorsed by the American College of Emergency Physicians. EDIE packages the collective data of every ED visit a patient has had, and offers that information in a useful way to ED clinicians.

EDIE, however, only tracked ED visit information. In Oregon, as a rare disease database bill moved through the state legislature, Jennifer Knapp and Adrenal Insufficiency United were able to get support to have the EDIE system offered to rare disease patients, though the system will only cover rare disease patients in Oregon and Washington State to start. The EDIE system is found in other states, but not yet used by all emergency rooms in those states, so the system may not be available to help rare disease patients elsewhere.

The hope for rare disease patients, like those with adrenal conditions, is that a database will be available for them that will share their personal needs with any doctor, emergency or otherwise, so that a viable playbook based on their medical history will be available. And, as time goes on, hopefully all hospitals, EDs, and clinics will have access to this database. Until then, there may be available options for patients right now. Because no such system currently exists nationally with perfect coverage, we suggest to our readers that they discuss with their primary care physicians if some such system is available in their area. It may be a network that covers the whole state, or perhaps just a few hospitals in their county. But, even that can help in a crisis, as emergency clinicians won't have to speculate on a course of basic treatment for adrenal insufficiency.

One possible option to help our readers is Smart911. It is a free online service that is meant to connect with emergency responders with a 911 call, and will share information with such responders. The information shared is entered by the patient in an account they create, and may include a wealth of information about them or their family, to be made available to first responders. This includes medical information, so adrenal patients can offer the details of treatment needed in a crisis. The Smart911 service is free to all US citizens. Services are paid for by public agencies ensuring free and equal access. You will be asked to update your information every six months. Although Smart911 is a nationwide service, it is not available in every municipality yet. Automated delivery of a Safety Profile to local law enforcement, medical, and fire responders is dependent on local public safety agencies installing the Smart911 technology. Please visit www.smart911.com and enter your zip code to find out if Smart911 is available in your area. Currently, we have no firsthand knowledge on the reliability of this service for adrenal patients since we have not heard from any of our members about it. We will keep you posted on any future developments.

Rare Art Contest

The 2017 Rare Artist Contest is currently underway, and voting is still open. The EveryLife Foundation for Rare Diseases invites all members of the rare disease community to visit their Facebook page to vote on art created by rare disease patients. The art is divided into categories by age and format, and the artist whose work is voted by the poll as the winner in each category will win a prize.

All reward recipients will have their work displayed during Rare Disease Week on Capitol Hill at the Rare Artist reception in Washington, DC on February 28th, 2018.

Entries into the contest will only be accepted until December 7th, but voting will continue up to December 21st.

To learn more and cast your vote, visit:
<https://tinyurl.com/y83vx3qx>

Action for Adrenal Awareness

Kim Burnette and the Action for Adrenal Awareness group on YouTube have a new video, starring Alabama support group leader Dana Baker, about advocacy and caregiver preparedness.

You can see the video on their channel at:
<https://tinyurl.com/yapxadpk>

Luciana Gates

NADF is sad to report that former Kansas support group leader Luciana Gates has had to step down from her position due to health issues. Luciana has to focus on her own personal health, and as such can not handle the duties of also running a support group. We at NADF are wishing her the best of luck, and know that our readers are wishing her the very best as well.

NADF thanks Luciana for her years of work as Kansas's support group leader.

Jan Judge

Jan Judge will be stepping down from the position of NADF's Support Group Coordinator, in order to focus on personal responsibilities and her work as support group leader for Southern New Jersey, and Southeastern Pennsylvania. As Support Group Coordinator, Jan is responsible for helping to manage the network of all support groups under our purview in the US. Often she fills in to help pick up the slack when local support group leaders are otherwise engaged, and her wealth of experience as a support person and advocate for adrenal disease is one of NADF's most valuable resources. She will be vacating the position of Support Group Coordinator by November 30th, but will remain as a support group leader.

There are simply too many things to thank Jan for. She has been involved in so much of NADF's advocacy work, and has been of great assistance to NADF's office. We thank her, and will continue to enjoy collaborating with her.

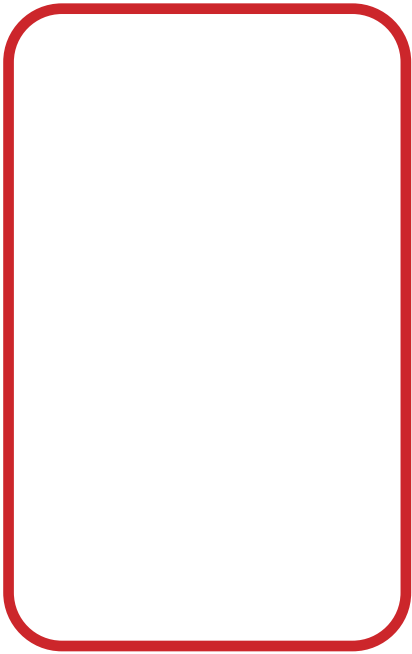
ALD and Newborn Screening

Since 2012, X-linked Adrenoleukodystrophy (X-ALD) families and researchers have been pushing for legislation to add X-ALD to the Recommended Uniform Screening Panel in the USA for newborn screenings. Gradually, funding and support have X-ALD screenings added in various states. A four million dollar award was granted to support state newborn screening programs to screen for genetic disorders that included X-ALD.

Now, since 2016, nine other states have included X-ALD as part of newborn screening, and lobbying continues in many other states to follow suit.

X-ALD treatment is most successful when implemented early, and as such newborn screening is the best way to diagnose it. If untreated, it can lead to both neurological damage and lifelong adrenal insufficiency.

Lisa Markland and ADSG on Facebook



After 5 ½ years, Lisa Markland is stepping away from all other duties with the Adrenal Diseases Support Group (ADSG) she founded on Facebook. Lisa has been a driving force in getting the group up and running, and then helping to manage its many facets. The ADSG network has been a pleasant companion with NADF, reaching and connecting people as far as the Internet will allow. While she turned over leadership of the group a couple of years ago, she has been advising and taking on many group duties since. She's now stepping back to let the group run independently.

Lisa is not taking time off, however (though she certainly deserves a break). She's going to be focusing her efforts on other adrenal disease related support and advocacy issues that are beyond the purview of the group. She is turning her attention to help with legislation for an adrenal disease awareness week, and writing an e-book about adrenal disease. Previously, her time was taken up with daily work with the ADSG, and now she is freed up to take on other challenges.

Lisa will still be working with NADF as a volunteer copy editor, and will hopefully be a resource and friend to us for years to come.

Editor's Note: Lisa has also corrected a slight error in some information about the ADSG's medical Road ID offer. For those who cannot afford to pay for their own, even with the discount offered to ADSG members, no shipping is required either. A corrected version of the notice is included on page 2.

Untethered Storms

This year, parts of the coastal US were devastated by hurricanes. Friends of NADF like support group leaders Pam Kimball and Mary Case, wrote to us with stories about how chaotic it could be for the people most touched by the storms. In such cases, adrenal insufficient people are at a very high risk of being put into a crisis, and with infrastructure and hospitals potentially in ruins, proper treatment is even more difficult to find.

In Puerto Rico, due to the destruction and havoc created by storms, many were left without any help. NADF has reports of

Addisonian patients being left stranded without their medication, or needing to flee to the mainland only to find that there was no way to get their prescriptions through when their doctors and hospitals were left without methods of communication.

NADF cannot stress enough the importance of preparation for the unknown cataclysms that can occur, especially for people with adrenal conditions. We also cannot stress enough our hopes that survivors will be able to find some solace of normalcy as soon as possible.

Affordable Care Act News

Since its passing legislature, the Affordable Care Act (ACA), also known as "Obamacare" has been quite controversial in the political ring. But as politicians debate the issues, patients must actually live with it. This year, attempts were made to repeal or significantly alter the ACA, forcing patients to consider living without it.

For some, the ACA has been very beneficial. Generally speaking, rare disease patients benefit from the ACA. Its repeal could mean skyrocketing premiums for some rare disease patients, and a loss of coverage for previous conditions. For already diagnosed adrenal patients, this would be very problematic. However, the ACA as it exists today has its own faults that have yet to be addressed. While many health insurance markets have lowered or controlled premiums, premiums in other markets are rising. In part, this is due to some insurance companies abandoning certain state health insurance markets all together, because they are finding it not worth trying to compete in those markets with the ACA in place. Less companies in those areas means less choice and competition. Cost shared health networks are also problematic for certain people in the rare disease community, if the scope of what they are covered for doesn't include their special needs over people with average overall health. Even in areas where premiums have remained relatively the same over the years, copays and deductibles have risen.

Attempts to have the ACA repealed have failed to pass in Congress due to some key bipartisan support. This included a "total" repeal, in which it was proposed to simply tear down the ACA entirely and replace it with new legislation. This was considered too extreme by many, and it did not pass the Senate. Following this, a "skinny" repeal was attempted in the Health Care Freedom Act, which would not dismantle the ACA entirely. This also failed to pass the Senate. A final attempt in September to consider a bill that would repeal and replace the ACA was reworked so it might be more successful, but still notable opposition stood in its way, and the Senate decided not to vote on the bill at all before the September 30th deadline. As such, it's likely the ACA will still be in place until Congress is next in session.

However, even with the ACA still intact, things can be done to both hinder or help the current health insurance situation in the USA. A compromise has been reached to try and amend, though not remove, the ACA. This move has been controversial, with premiums expected to lower for some people, but raise for others, and an uncertainty of the cost to tax-payers over time.

Health insurance and the ACA are a delicate, and very complicated issue right now. Adrenal disease patients, like other rare disease patients, could suffer in being able to afford coverage if things stay the same or don't change for the better. Until a solution is presented, lawmakers should not rest or waste time.

MAILBOX



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

This weekend I finished a 53 mile backpacking hike along the PCT in Oregon. And my body rocked it! I had to stress dose and almost double dose every day, but I made it. It was over 111° during the week so I was having to carry over 20 pounds of water a day, with plenty of salt to stay hydrated. My pack was over 40 pounds with the weight of food and water for 6 whole days on the trail, and I couldn't be more excited! This is a tradition my father and I take on every year, and after my diagnosis last year I was worried my body wasn't going to make it. But I proved myself wrong. Sure I am paying for it today, and it will probably take a week before I feel normal again, but I am so

grateful for this victory; and cannot wait to hit the trail again next year! (You might be able to see my Addison's patch on my pack too!)



Thank you for all that you're doing for those with adrenal diseases. It means a lot coming from a person with one. [...] I learned a lot through this, and feel as though others did too. Thank you for what you're doing.

Q & A

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



Q. Since labs can measure antibodies to the adrenal cortex with the anti-21 hydroxylase test, is there any thought to make that the diagnosing test for primary adrenal insufficiency, and throw out the ACTH stimulation test?

A. No, the test for 21OH antibodies does not replace the ACTH stimulation test, but is a useful adjunct. If the antibodies are positive it simply means that the process of autoimmune adrenal insufficiency is taking place, so if there are signs and symptoms of adrenal insufficiency, it establishes the etiology. However, some people may not progress all the way, so positive antibodies does not prove that the adrenals are already destroyed. In addition, there are other causes of primary adrenal insufficiency besides autoimmune destruction, so ACTH stimulation testing is still the gold standard for proving significant adrenal insufficiency. Plus, it is useful in many cases of secondary adrenal insufficiency.

Q. Can I take DHEA if I had breast cancer 25 years ago? I think I can't.

A. There is no data on this issue, but I would suggest avoiding DHEA with a history of breast cancer.

Q. Can you offer any insights into getting the balance correct for florinef/salt/electrolytes/steroids during exercise? When I work out hard, the cramping gets really bad and it is hard to recover.

A. Balancing mineralocorticoids can be tricky, especially for athletes. One problem is that fludrocortisone is very slow acting and long lasting, so it is difficult to titrate is for a single workout. It is probably better to leave the dose stable if blood pressure tends to rise when the dose is increased. It may be easier to just use salt and fluids plus a slight boost of hydrocortisone (which has mineralocorticoid activity) for the work outs.

Q. Is it safe to take Low Dose Naltrexone with Prednisone? I have Addison's Disease as well as CFIDS/FM. I began LDN but seem to be getting weaker like my pre-Addison's diagnosis. Any information would be very helpful. I've researched and not found any contraindications.

A. There is no interaction between naltrexone and glucocorticoids. However, the side effect profile of naltrexone includes symptoms that are very similar to adrenal insufficiency, including nausea, dizziness and weakness. Therefore, one should be cautious about interpreting the symptoms.

Linda O'Leary

Long time support group leader for Central Florida, Linda O'Leary, is sadly stepping away from the position to help her husband through personal health issues. Linda has offered NADF many years of caring and generous volunteer work to helping others. Her dedication to us and the people in her support network was of tremendous help.

NADF wishes her and her husband the best.

Retraction

In a previous edition of the NADF News®, an article was presented with a report we received from one of our members about the company Pfizer at some point developing an auto-injector pen for Solu-Cortef®, as a new way to quickly treat an adrenal crisis, similar to an allergy epi-pen (NADF News® Vol. XXXII #2). Apparently, while there has been discussion of such a medication being produced for a few years now, no such device has been developed, and according to a representative Pfizer is not currently developing one either. We apologize for the inconvenience.

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 group held a small meeting on the 11th of November. New members were introduced and brought up to date with information about adrenal insufficiency, and how to advocate for their own best care. Their next meeting is planned for January 13th, 2018.

Minnesota: Support group leader Julie Zaruba Fountaine is resigning from the position due to a heavy schedule and personal commitments. NADF thanks her for her past years of help and generosity.

New Jersey/South/SE Pennsylvania: This group held a meeting November 3rd, where attendees shared their personal stories of struggling with health and adrenal disease, including problems with hospital visits. Their next meeting is currently planned for April of 2018.

Northern Illinois: A caring volunteer of this group has implemented a project to distribute by postal mail adrenal crisis alert facsimiles to every firehouse in Chicago.

Oregon: This support group held a meeting on Saturday, September 23rd. The report from the group leader says the meeting went well, with six families attending. The support group leader handed out some of NADF's educational and merchandise items, and made a connection at the meeting with someone with local hospital contacts. Their hope is to improve hospital awareness and care for people with adrenal insufficiency.



The NJ/PA Support Group

MEMBERSHIP

NADF is once again printing renewal dates on the address labels for postal mailed newsletters. To check to see if your membership has expired, please refer to the date printed there.

NADF BOARD/MEDICAL ADVISORS

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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.

Dear NADF: Please accept my tax-deductible donation of: \$25 \$40 \$50 \$100 \$250 \$500 \$_____

To donate using a credit card, please visit the NADF Website at www.nadf.us, and choose the one of options under the "Donate to NADF."

THANK YOU FOR YOUR GIFT!

As always, a donation of \$25 or more entitles you to an annual membership in NADF, and you will receive the NADF Newsletter quarterly. Please be sure we have all of your current/correct information by filling in the form below. All information provided is confidential and will not be sold or rented under any circumstances.

NAME _____ TEL. NO. () _____
 STREET _____ CITY _____
 STATE _____ ZIP _____ E-MAIL _____

I RECOMMEND MY PHYSICIAN: Name _____ Specialty _____ Location _____

ADRENAL DISEASE: Addison's Cushing's CAH Other: _____

I give NADF permission to share my contact information (e-mail & phone number) with other people with adrenal disease who might want to share.

Please make checks out and mail to: National Adrenal Diseases Foundation, P.O. Box 566, Lake Zurich, IL 60047

NADF SUPPORT GROUP CONTACTS

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Missouri/Kansas City:	Lynette Trammell (913) 708-1121; lyntrammell@yahoo.com	Specialty Support Groups	
Missouri/So. Illinois St. Louis:	Kandace Fisher; kandacef82@gmail.com	Cushing's Specialty Support Group:	Jennifer Schutte (862) 219-9062; jenschutte@gmail.com
New England (Boston):	Roberta Lasky (978) 658-3245; Roberta.Lasky@att.net	Isolated Central Adrenal Insufficiency:	Sabra Rahel; sabrarahel@yahoo.com
New Jersey/North:	Diane Moschetta (973) 778-8440; dmoschetta@yahoo.com	Spanish Speaking Adrenal Patients:	Patricio Camacho (323) 919-7876; camacho.patricio09@gmail.com
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
North Carolina:	Anessa Powell (704) 458-5448; anessa@nadf.us	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
Ohio:	Susie Mathis (513) 290-5025; nadcincinnati@group@gmail.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
Rocky Mountain (Wyoming/Montana/Idaho):	Sarah Reilley; rmadrenal@group@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
South Carolina:	Michele Gregory (864) 723-0075; chele8367@gmail.com		

CONTACT YOUR GROUP ON FACEBOOK

Alabama: www.facebook.com/Alabama-Adrenal-Disease-Support-Group-641435065887735/
 Georgia: www.facebook.com/ActionForAdrenalAwareness/
 Indiana: www.facebook.com/events/231358943971934/?ti=cl
 Kentucky: www.facebook.com/home.php?m2w&refid=18
 Missouri/Kansas City: <https://m.facebook.com/groups/2037889206442289>
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