## NATIONAL ADRENAL DISEASES FOUNDATION

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Dear NADF Members and Friends:

I am hoping that you are all well and enjoying the Summer.

We have had some important happenings at the NADF since April 1st of this year, with Jennifer Thorstad's Walk for Addison's - Walk for Life fundraiser (see story) and the breaking news about sulfites in cortisol-type injectable preparations (see story and product list).

NADF has a new affiliated Addison's ladrenal support group due to the selfless initiative of Melinda Robare of Louisiana. This group will provide much needed support to a vital area. Thank you, Melinda!

Best wishes for good health and good times for you and yours for the rest of the Summer!

Melanie Wong Executive Director

#### WARNING! SULFITES IN VARIOUS CORTISOL-TYPE INJECTABLE PRODUCTS

Because of the harrowing experience of an NADF Member, we've had our eyes opened to the fact that several cortisol-type injectable products available for prescription contain sulfites. If you don't have a sensitivity to sulfites, this information may not concern you, but...if you do have sulfite sensitivity, use of your injectable product or infusion with such a product at your local emergency treatment center during a crisis could potentially threaten your life. If you have adrenal insufficiency and sulfite sensitivity, here are some suggested steps to take to insure safe crisis care:

- 1.) Compare the injectable cortisol-type product you have in your possession to the list below. If your product is listed as containing sulfites, talk to your physician immediately about acquiring a new prescription for a product that doesn't contain sulfites.
- 2.) Inform your local emergency care treatment centers about your adrenal insufficiency (Addison's disease, if that helps them understand), your potential need for crisis care at their facility and your sensitivity to sulfites.

Along with phone calls to check on products currently in use, you could also use copies of the NADF Emergency Crisis Care Cover Letter and Instruction Sheet, adding Allergic to Sulfites and/or Sulfite Sensitivity in bold lettering to the instruction sheet, and postal mailing them out. (Copies of this item were printed in NADF News®, VOL. XXI, No. 4 • 2006. If you need a copy of this NADF hand-out, e-mail NADF at NADFmail@aol.com or call headquarters, and request a copy. If you need yours postal mailed, please be sure to leave your postal address.)

NADF owes a BIG thank you to Member Lynn Wrobleski for allerting us to sulfite containing cortisol-type products so that we could alert others, and thereby possibly save lives.

## INJECTABLE PRODUCTS AVAILABLE FOR PRESCRIPTION

UPDATED 5/20/08

(We would like to thank NADF Pharmaceutical Liaison volunteer Les Sass for the great job he did hunting down sulfite information to complete this list!)

#### **PFIZER**

Customer service 1-800-533- 4535, 1-888-691-6813, medical information 1-800-438-1985

Solu-Medrol (no sulfite) (methyl prednisolone sodium succinate) is in a powder form in a vial. Sealed cap. Must be mixed with bacteria static water for injection.

125 mg vial 40mg vial

500mg vial 4ml 8ml

1gm vial 8ml 16ml

2gm vial - comes with mix/dilutant

Solu-Cortef (no sulfite) (hydrocortisone sodium succinate) powder form in "acto-vial"

100mg/2ml

250mg/2ml - 25/box singles

500mg

1gm

4mg/1ml (contains sulfite!)

#### **AMERICAN REGENT**

Customer service 1-800-645-1706 & 1-800-874-2334

Dexamethasone in liquid form in vials (contains sodium sulfite!)

4mg/1ml vial

4mg/5ml vial

4mg/30ml

#### **BEDFORD**

Customer service 1-800-562-4797

Methylprednisolone (no sulfite) powder in vial, must mix with bacteria static water.

125mg vial 40mg vial 500mg vial

1gm vial

#### **HOSPIRA**

Customer service 1-877-946-7747

A-Methapred (methylprednisolone) (no sulfite) powder in vial, must mix with bacteria static water.

125mg

40mg

A-Hydrocort (hydrocortisone) (no sulfite) powder in vial, must mix with bacteria static water.

100mg

#### **TEVA**

Customer service 1-800-729-9991

Dexamethasone (contains sulfite!) liquid form in vial

10mg

Methylprednisolone (no sulfite) liquid form in vial with metal cap and rubber center.

40mg/1ml vial

40mg/5ml vial

40mg/10ml vial

80mg/1ml vial

80mg/5ml vial

#### **ABRAXIS**

Customer service 1-888-386-1300, medical information 1-800-551-7176

Methylprednisolone (no sulfite) in powder form, must mix.

1gram vial

125 mg vial 40mg vial

Dexamethasone sodium phosphate in liquid form

10mg/1ml (no sulfite)

## DUAL-RELEASE HYDROCORTISONE NEWS

Greg Batcheller, Chief Executive Officer of DuoCort Pharma AB of Helsingborg, Sweden reported directly to NADF that their dual-release hydrocortisone product DuoCort<sup>TM</sup> has been granted Orphan Drug Designation by the U.S. Food and Drug Administration.

Now don't get too excited. That doesn't mean that DuoCort is being marketed yet. It just means that when it does hit the market, it will have exclusive rights to that market for seven years. To read more about DuoCort Pharma's new adrenal hormone replacement currently in development, please visit their website at www.duocort.com

## SAD NEWS

NADF is sad to report that Canadian journalist Christy Lapi, Canadian Addison Society's (CAS) Vancouver Island contact, passed away in April at 60 years of age due to lung cancer. (She was not a smoker.) Christy will be missed by her CAS family and friends, as well as by the many readers who enjoyed her journalistic talents.

## UNDIAGNOSED DISEASES PROGRAM

from: http://rarediseases.info.nih.gov/Resources.aspx?PageID=31 (Reprinted Using the Fair Use Act)

Some patients wait years for a definitive diagnosis. Using a unique combination of scientific and medical expertise and resources at the National Institutes of Health (NIH), the Undiagnosed Diseases Program pursues two goals:

- 1. To provide answers to patients with mysterious conditions that have long eluded diagnosis.
- 2. To advance medical knowledge about rare and common diseases.

The program is trans-NIH in scope. It is organized by the National Human Genome Research Institute (NHGRI), the NIH Office of Rare Diseases (ORD) and the NIH Clinical Center. Many medical specialties will contribute expertise

needed to conduct the program, including endocrinology, immunology, oncology, dermatology, dentistry, cardiology, and genetics, which are represented among the dozens of participating senior attending physicians who may participate in the program's clinical research. Any longstanding medical condition that eludes diagnosis by a referring physician can be considered undiagnosed and may be of interest to this clinical research program. Of the total number of cases that may be referred to this program, a very limited number will be invited to proceed in the study at the discretion of the program's medical team. For more information please call (866) 444-8806.

## A SUCCESS STORY

A NADF affiliated support group (SG) leader/facilitator shared a "success" story with us. A mom contacted NADF because she was concerned about her son. The support group leader assigned to this contact talked to the mom, and NADF e-mailed and postal mailed the mom information. Although the son was against getting involved with a support group, his mom insisted he contact the group and attend a meeting. He finally contacted the group, and the leader and he talked a number of times. He attended their last meeting. After the meeting, the young man shared that he had been very depressed to the point of having suicidal thoughts, but two things keep him going: primarily, his

children, but also thinking about all the people in the support group meeting room who shared their stories and are able to live with this disease. He had lost hope, but said after hearing the stories he got the determination he could live with it too. He's still being diagnosed by a new endo, but he's on the road to recovery and in his last phone call with the NADF Support Group Leader/Facilitator, wanted her to thank NADF for saving his life.

It is purely NADF's pleasure, sir. Thank you for sharing your uplifting story with us.

## NEW BOOK ON AUTOIMMUNE DISEASE

#### THE AUTOIMMUNE EPIDEMIC

Bodies Gone Haywire in a World Out of Balance—And the Cutting Edge Science that Promises Hope

by Donna Jackson Nakazawa

NADF would welcome reviews of this book for possible publication in an upcoming edition of the NADF News®. To submit your review, please e-mail a copy to NADF News Editor Debbie Benish at us@eohio.net or postal mail a copy to NADF, 505 Northern Blvd., Suite 200, Great Neck, NY 11021.

## RAISING FUNDS WITH GOODSEARCH.COM

Thank you to everyone who has already used Goodsearch.com for shopping and internet searches. To date, you have helped to raise almost \$600.00 for NADF.

Haven't tried Goodsearch.com yet? It's easy. Go to "Preferences..." on your internet search engine, and change your homepage address to www.goodsearch.com At the GoodSearch page, select NADF or National Adrenal Diseases Foundation as your charity of choice.

Goodsearch makes donations to the NADF for each search conducted from their homepage and each item purchased through GoodShop.

#### **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.

### WALK FOR ADDISON'S - WALK FOR LIFE

by NADF Executive Director, Melanie Wong

On my way to Fridley, Minnesota to speak at Jennifer Thorstad's Walk for Addison's - Walk for Life fundraiser, I stopped first in Ferryville, Wisconsin to pick up my dear friend Karen, who had agreed to do volunteer work for this event, then continued on to Minneapolis for our Friday night stay at the lovely LeBlanc House Bed & Breakfast. We of course got lost. I guess we found Minneapolis very confusing. But with the help of my GPS (global positioning system), we finally found our place of lodging at about 11pm. Long hours on the road.

The LeBlanc House was lovely, and owned and overseen by very kind people. Saturday morning, we were treated to a delicious Swedish breakfast prepared by LeBlanc Innkeeper Linnea, consisting of fresh fruit and yogurt, coffee cake, crepes with loganberries and maple syrup, bacon, coffee and orange juice.

Immediately after breakfast, we packed up the car with the material we would need for the Walk for Addison's - Walk for Life event, and headed to the Springbrook Nature Center (http://www.springbrooknaturecenter.org/) in nearby Fridley, MN. It was a snowy morning, with a bitter blowing wind.

In a picnic pavilion right inside the entrance to Springbrook, Karen and I found Jennifer and her close knit family, along with Northwest Passage High School's wonderful teachers and Jennifer's classmates/teammates. The team had made up a banner announcing the Walk for Addison's - Walk for Life groundbreaking event, and suspended it on one side of the picnic pavilion. Everyone was trying to keep warm in the strong wind while donning their "walk" t-shirts over their heavy clothes.

The turn-out for the Walk for Addison's - Walk for Life event exceeded everyone's expectations. At 10 am., the walkers set out for the trails of the heavily wooded Springbrook Nature Center. Thankfully, the trees protected the walkers from the wind and they reported feeling quite warm while they were exerting themselves.



NADF Exec. Director Melanie Wong speaking to the Walk for Addison's - Walk for Life attendies.



Walk for Addison's - Walk for Life attendies settled in to listen to people speak.

Because of the unrelenting bitter wind, we implored Springbrook's kind personnel to allow me to deliver my talk in their Interpretive Center instead of in the exposed picnic pavilion. Even with a scheduled kid's birthday party taking place, the wonderful people at Springbrook let us congregate and use their lovely museum/zoo-like building to conduct our presentation.

After the walk, Jennifer took the opportunity to thank everyone involved, then introduced me. I was nervous, and didn't orate as well as I had wanted, but I attempted to tell everyone a bit about NADF's history, purpose and goals for the future. At the end, I asked for questions, but failed to mention to the audience that they could ask questions about adrenal disease if they wanted. No questions were proffered, although many people came to speak to me individually afterward.

It was wonderful to be in Fridley helping Jennifer Thorstad achieve her scholastic requirements while raising funds to help NADF reach its goals and dreams. I finally met and was able to warmly hug people I had only interacted with via email or the telephone. Karen and I spent an additional night in the LeBlanc House, allowing the Addisonian (me) to recover from the event before we started home.

The next day, NADF invited the Thorstad family out for lunch at their restaurant of choice in gratitude for their hard work and generosity.

In summary, Jennifer's fundraiser was a huge success, raising a current grand total of \$6,024.00, with more promised. NADF would like to make special mention of young Addisonian Dan Holland for the money he raised for the Walk for Addison's - Walk for Life event, totaling an amazing \$1,511.00. Thank you so much, Dan!

We are hoping that the Walk for Addison's funds, combined with monies raised from the various fundraisers our selfless members have initiated over the past couple of years —

\$ 963.60	Dusty Hardman's Grant Tetons Races Marathon
\$2,006.00	Heather and Dave Nagy 2006 Labor Day Mackinac Bridge Walk
\$6,040.40	Dusty's Race To Save Lives Triathlon
\$ 500.00	The Motorcycle Emporium's Jane Holdener Benefit Memorial Poker-Run and Cook-Out

#### GRAND TOTAL \$15,534.00 —

NADF may finally be able to undertake mass mailings of a highly illustrated educational flyer which will list the various symptoms of adrenal disease, along with full-color photographs of undiagnosed individuals. With this project, NADF is hoping to remind the entire U.S. diagnosing medical field (general practitioners and emergency room doctors) to think of the adrenal glands, with the ultimate goal the elimination of death from undiagnosed adrenal disease. With the generous and selfless fundraising efforts of Jennifer, Dusty and Heather, we are hoping to save some lives!

"Walk for Addison's - Walk for Life" T-Shirts are still available. To order yours, please use the order form below.



[back row] Walk for Addison's - Walk for Life originator Jennifer Thorstad, Erin Folssum, Carla Staffon. [front] Neal Todd.



T-Shirt Front



T-Shirt Back

T-Shirts are white, and all of the images/logos are in NADF blue only.

Please send a check or money order (payable to NADF) for your total order amount, along with this coupon to: NADF, 505 Northern Blvd., Suite 200, Great Neck, NY, 11021

#### T-SHIRT ORDER COUPON

Quantity

Price:	\$12.50 ea., \$13.50 ea. for XX	L Medium
Name		Large
Phone number	E-Mail	
	Ship To Address	XL
Street (No P.O. boxes)		XXL
O'th .	04-4- 7% O-4-	

## **Q&A**By Paul Margulies, M.D., FACE, FACP

I have Addison's and I also have Celiac. I know with Celiac that I have to take extra calcium and

vitamin D for osteoporosis. I was reading in your Q & A part that people with Addison's should also take extra calcium. How much calcium should I be taking? I'm a 60 year old female.

For most people I would suggest 1200 mg of calcium per day from calcium carbonate or citrate, plus 800 to 1200 units of vitamin D. If constipation is a problem, add magnesium 250 mg per day to prevent the constipating effect of the calcium. Celiacs often have a significant malabsorption of vitamin D. The serum vitamin D level should be checked. If it is lower than normal, even higher doses of vitamin D may be needed, sometimes prescription strength doses. A bone density every 2 years would be useful to assess the response to the calcium and D.

I am a 54 year old female who was diagnosed with Addison's Disease five years ago. For a long time, I have wanted to try one of the dermal fillers for the deep folds around my mouth. Is there one that is safe and effective for me to use? I have asked my endocrinologist, but he is not familiar with the products. I have an appointment with my dermatologist next month to have some keratoses removed. I would like to talk with him about the fillers at that time.

I am not familiar with these products either. I can't think of any reason you would not be able to use a skin therapy that is safe and effective for other people. As long as it does not cause any serious stress on your body, the Addison's disease should not be a factor.

(edited for length) I'm a 67-yr. old female with Addison's and hypothyroidism. My concern is my fluctuating, sometimes very high ACTH numbers, which I started logging in 1989. I'm frightened of an increased hydrocortisone dose. My stomach is quite distended since the beginning of year and I have gotten thick in waist area. I have also developed terrific loss of bone in my jaw the last few years. I felt much better on a lower dose. My question is: What is the highest "safe ACTH read" recorded? I know we all react differently to some medications and I really do not want to take more steroids. I sometimes feel they do more damage than good. PLEASE HELP!

Stop measuring ACTH. The level has no clinical value after the initial diagnosis of Addison's disease. The dose of hydrocortisone should be adjusted to the clinical response - sense of well being, energy, stamina, weight gain or loss, blood pressure fluctuations, appetite, etc. It is important to take enough hydrocortisone to eliminate the symptoms of adrenal insufficiency while avoiding excessive replacement that will cause signs and symptoms of cortisol excess. Useful blood tests include electrolytes (sodium and potassium), and plasma renin (especially for adjusting the dose of fludrocortisone). If there is significant hyperpigmentation despite hydrocortisone, this is a clinical sign of high ACTH. Usually the hyperpigmentation will resolve when the dose is adequate, but may temporarily return at times of stress. This can be useful as a guide to therapy, but should be used in conjunction with the other signs and symptoms of adrenal insufficiency in making adjustments in dosage.

In order for a pediatrician to refer a child to a pediatric endocrinologist, must the blood work show low NA and high K, or can other symptoms suffice? Does someone with Addison's ALWAYS have low NA and high K? Thanks!

Abnormal electrolytes can be a useful sign of adrenal insufficiency, but they are not a necessary clue. A referral should be made if there are significant symptoms and physical findings. Some Addisonians have an abnormal ACTH stimulation test in the absence of electrolyte abnormalities.

# NADF MEMBER WRITES PAPER ON JOHN F KENNEDY

NADF member Aida Alvarez wrote a research paper on John F. Kennedy. Unforunately, the document is too large for printing in the NADF News® or for posting on the NADF website (www.nadf.us). Aida's work has been added to the NADF Library.

If you would like a copy, please send a request e-mail to NADFmail@aol.com, and we would will e-mail it to you (in PDF format). To have a hard copy sent to you via postal mail, please send a check or money order for \$1.80 to cover postage, materials and handling, made out and sent to: NADF, 505 Northern Blvd., Suite 200, Great Neck, NY 11021.

## WEB SITES OF INTEREST

Consumer Advocates in Research and Related Activities (CARRA)

http://carra.cancer.gov/

Office of Rare Diseases, NIH http://rarediseases.info.nih.gov/Default.aspx

Agency for Healthcare Research and Quality http://www.ahrq.gov/

## 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.

*New! Louisiana:* Due to the giving nature of New Orleans suburban resident Melinda Robare, NADF now has an affiliated Addison's/adrenal support group in Louisiana. Thank you so much, Melinda, for volunteering to help lend support to others! If you would like to offer your help to Melinda, or just drop her a line to say "hi" and "thanks", she can be reached at (504) 415-7547; e-mail: robare@attglobal.net

Alabama, Connecticut, Indiana, Massachusetts (Boston), The Carolinas. Oregon, Tennessee, Virginia, Wisconsin: There are several adrenal patients in these areas, and no support groups. If you live in one of these locales and would like to lend support to others, please contact NADF Support Group Coordinator Jan Judge at (856) 354-6029 or e-mail JanPT@aol.com

California/Los Angeles: This group meets at the Irvine Medical Center about every 3 months. Their last meeting was held on June 14th. Check out their new website at http://www.socalad.info The OC/LA Addison's Support Group's next support group meeting will be held on the second Saturday in September from 1-3 p.m. Contact the group for more details.

*California/San Francisco:* This group is hoping to hold a meeting on Saturday, September 27th. Historically, the NorCal group has held more of a social meeting - potluck, etc.- at this time of the year. This year, they plan to have some fun and take care of the evolution of the group at the same time. Contact the group for more details.

Florida/Southern: The South Florida NADF Support Group membership is growing in numbers and they hope to have a lunch get together soon to meet everyone, in a location that is accessible for members who are spread out over the Naples, Miami, Ft. Lauderdale and West Palm Beach areas. Contact the group for more info.

*Iowa:* This veteran group met April 27th in Webster City with 11 in attendance. Their featured speaker was Chris Donner-Tierman, Pharmicist. She suggested that attendees be sure to have our doctor's mark the "no substitutions" on our prescriptions if they are not able to take the generic brands. The Iowa Addison's Support Group's next meeting will be on September 21, 2008. Contact the group for more details.

*Michigan:* This group met in April at Howell and had a wonderful presentation by a member on Live Vaccines and Caregivers. Their next meeting will be held in October where they hope to have a Nutritionist as a featured speaker. Tentative plans for a Spring 2009 meeting envision an endocrinologist as a guest speaker. Contact the group for more details.

New Jersey/SE Pennsylvania: This group held a pot luck lunch on May 17th. They had eight members and family members, and welcomed two new people, one from Delaware and one from Maryland. Their next meeting will be in September. Contact the group for details.



Attendees of the NJ/PA Addison's Support Group Meeting (from left to right) Jeff Korostoff, Gairda Lauterbach, Jan Judge, Deb Kooperstein, Nell Deibert, Sue Mee and Yale Kooperstein.

*Ohio:* This group will meet again on October 11, when their topic will be "Addison's ABC's", a sharing of the basics especially for newbies. They are hoping that all the "old hands" will come to share what they've learned about this disorder. COAST has had a lot of new members at their last three meetings, and thought it might be a good idea to review the basics of Addison's Disease. Those interested may call Marianne Kowalchuk at 937-767-9117 or 937-554-6383, for more info.

*Texas/Central:* This group held a support group meeting on June 7th in Killeen, Texas.

#### NADF BOARD/MEDICAL ADVISORS

Timothy Skodon, *Treasurer* Nancy Harms
Marianne Kowalchuk Bonnie Wolff
Erin A. Foley-Moudry, MPH

Paul Margulies, M.D., FACP, FACE—Medical Director Maria New, M.D.—Medical Advisory Board Phyllis Speiser, M.D.—Medical Advisory Board Melanie G. Wong—Executive Director

#### Volunteers:

NADF News® Editor: Debbie Benish Website: Kate von Tungeln Support Group Coordinator: Jan Judge Secretarial Help: Kalina Warren Pharmaceutical Company Liaison: Les Sass Long Island Liasion: Megan Anderson

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.

## **NADF SUPPORT GROUP CONTACTS**

STATE				Location
STREET				
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your current/correct	information by filling in the form	ual membership in NAD below. All information p	DF, and you will receive the NAD provided is confidential and will r	F Newsletter quarterly. Please be sure we have all on the sold or rented under any circumstances.
			ve-designated amount 🔲 C	Credit card donation made via JustGive.org
Dear NADE: Dlassa	accent my tay daductible de	nation of \( \precedent  \pr	   \$40	)
New York City:	Linda Lake (212) 735-6 lindalake@rcn.com	5575;		southernortaino addisonsociety.ca
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