

NADF'S COMPILATION FOR ADRENAL INSUFFICIENT ATHLETES

(compiled 3/24/08)
(edited 5/10/14)

From **Q & A by Dr. Margulies, MD, FACE, FACP**, NADF News®, VOL. XIX, NO. 2 • 2004

Q. Can an athlete continue to perform at the same level with Addison's Disease with proper amounts of medication?

A. Although I am not aware of any professional athletes with Addison's disease, certainly many Addisonians can do strenuous exercise and participate in sports of all types. Each person needs to develop his or her own sense of balance between exercise and steroid dosing by trial and error. Extra fluids, salt and calories are needed, especially in warm climates.

From **Q & A by Dr. Margulies, MD, FACE, FACP**, NADF News®, VOL. XX, No. 1 • 2005

Q. I read all kinds of stuff regarding cardio-fitness. And I read all kinds of stuff saying that we with adrenal problems should not exert ourselves longer than 45 minutes or excess cortisol kicks in and will further stress our bodies. Can you give me some general guidelines as to length of time we can exercise in total and of that time how much should be spend on exertion vs. just a gentle heart rate increase? I hope that makes sense.

A. I believe everyone should try to stay physically fit with regular exercise and good diet. There is no specific restriction on exercise for people with Addison's disease. For general fitness, I suggest an aerobic routine like a treadmill for 30 minutes with added training exercises like weights if desired. There is nothing wrong with doing more exercise - just listen to your body. Make sure you stay well hydrated and replace salt as needed, especially if you are exercising in hot weather. If the exercise causes excess fatigue, it may be necessary to add a little extra hydrocortisone before the next routine. Start with an extra 5 mg and go up from there if needed.

From NADF News®, VOL. XX, No. 3 • 2005

Brittle Bones Can Affect Older Men As Well

Fractures less common but more lethal for men
than for women, experts say.

By E.J. Mundell

HealthDay Reporter

(Reprinted using the Fair Use Act.)

SUNDAY, July 10 (HealthDay News) — ...As for exercise, its benefits are more about balance than

bones, according to Weber. "Exercise's effects on the skeleton tend to be fairly modest," he explained. "When we prescribe exercise for older people we're doing it not only to help bone density but to increase strength and reduce their risk of falls."

Lane agreed. "You need two things for a fracture: bad bones and a fall. There's an easy way to tell if you're at high risk for falling: try standing on one leg for 12 seconds. If you can't do that, then by definition you're an unsteady individual who needs fall protection" such as sturdy shoes, a cane or walker, he said.

But failing balance can be restored, and one of the world's oldest interventions remains among the most effective. "The most successful method is Tai Chi," Lane said. "All of the YMCAs in New York now teach Tai Chi, and we send all the people who fail the one-leg test to the Y to learn it."

More information:

Bone up on bone loss at the American Academy of Orthopaedic Surgeons.

(SOURCES: Thomas J. Weber, M.D., assistant professor, medicine, division of endocrinology, metabolism and nutrition, Duke University Medical Center, Durham, N.C.; Joseph Lane, M.D., chief, metabolic bone disease service, Hospital for Special Surgery, Weill Medical College of Cornell University, New York City, and spokesman, American Academy of Orthopaedic Surgeons)

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From NADF News®, VOL. XXI, No. 2 • 2006

HORROR STORIES

Two more United States citizens have died from adrenal disease!
(Borrowed from the Addison's Disease Support Group
for Northern Illinois (ADSGNI) Spring 2006 Newsletter,
who was alerted to the story courtesy of NADF and
ADSGNI member Lisa Savegnago.)

"Wheaton North mourns sophomore"

By Jack Komperda and Justin Kmitch
Daily Herald Staff Writers
(reprinted using the Fair Use Act)

Kevin Newman was never the biggest kid in school. He wasn't the biggest on the football field, either. But friends and family said his heart made up for it. "He was little, but he was tough," said Sam Fawkes, a longtime friend who grew up down the street from the Wheaton North High School sophomore. "He was always a fun kid, always smiling and laughing."

Kevin, 16, died Wednesday of complications from Addison's disease, a hormonal disorder that causes muscle weakness and weight loss.

Fawkes recalled Kevin as an outgoing guy who talked him into playing youth football in elementary school through the Carol Stream Panthers organization and again later when they were freshmen at Wheaton North. "He was always the one lowering his shoulder and plowing over people," Fawkes said.

Steve Hoel coached Kevin on the sixth- and seventh-grade team in 2001 that defeated Wheaton in the Bill George Super Bowl. Kevin played defensive line and sometimes linebacker during his two years on the team. "The thing about Kev was his heart. He was always kind of the smallest kid on the team, but he was also the hardest hitting. He'd line up against a kid twice his size and put a wallop on him like he never saw coming from a little guy," Hoel said. "He never let his size be an issue no matter where he played on the field."

Kevin's father, Michael, said his son's enthusiasm for sports came from watching his older brother, Luke.

Beyond sports, his father said, Kevin was able to cultivate a close network of friends. "He was a fun, popular classmate," Michael Newman said. "He had lots of friends. He was a real boy's boy."

Fawkes said he joined more than 30 of his classmates from Wheaton North Tuesday at Central DuPage Hospital in Winfield. Most sat silent, while others cried during the night as they waited for word of Kevin's condition.

"Everybody loved him," Fawkes said."

It happened in Illinois, home of the largest NADF affiliated adrenal support group in the United States. Why? We are hoping that a NADF member, with the soul of a news reporter, will investigate, and get answers to these questions for us.

If you would like to hunt down the "ins and outs" of this story, please contact Melanie Wong at NADFMAIL@aol.com or call 1-516-487-4992...."

From NADF News®, VOL. XXI, No. 3 • 2006

NADF SPORTING NEWS

It was a summer of amazing athletic feats performed by individuals who have chronic adrenal insufficiency (Addison's disease).

DUSTY HARDMAN

On Sunday, September 3rd, NADF'S very own Idaho (Montana and Wyoming) Addison's Support Group Leader/Facilitator Justine (Dusty) Hardman ran the grueling Grant Tetons Races Marathon, held at the Grand Targhee Ski & Summer Resort in Alta, Wyoming. Why grueling?

The marathon was 26.2 miles long, with 23 miles of the race run on trails and only 3.2 miles run on road, all at an elevation of 5,000 vertical feet. It was the biggest physical challenge that Dusty ever faced.

She shared that she wasn't running the race to win. Her goal was to complete the race and to remind Addisonian's what can be accomplished.

During her eight months of training for the race, Dusty not only planned the race with a message for Addisonians in mind, but also went as far as to raise money to help NADF help others. She collected a grand total of \$963.60! We send a heartfelt thank you out to Dusty.

After the race, Dusty relayed, "The marathon was awesome. I finished 17th overall, out of 44. I am very happy with that finish, considering I just wanted to finish upright!"

You did so much more than that, Dusty. You inspired us all. Congratulations!

On Sept. 16th, less than two weeks after the Grand Teton Races Marathon, Dusty participated in a Trail Race and the weekend after that, hit the road again with a Bike/Run Race on September 23rd. Her accomplishments and stamina boggle the mind!

BAINBRIDGE

Dan Bainbridge, inspired by Dusty's athletic accomplishments, shared, "What a great thing you are doing, both for yourself and NADF. I am the father of a 16 year old boy who went through a serious Addisonian crisis at age 9. His doctor recommended that he stay as active as possible for his overall health and he has done just that. We hike, backpack and mountain bike together, but his main activity is crew (rowing).

He is starting his second year with the local rowing club (LGRC) and last year his boat won the gold medal at the Western Regional Junior Finals. Rowing is an intense form of exercise, like marathon running, but you two are both showing it can be done."

NADF sends a big WAY TO GO! and CONGRATULATIONS! to Dan's son.

HEATHER AND DAVE NAGY

While on vacation in Michigan, NADF Director of Fund Development, Heather Nagy, an Addisonian, and her husband Dave joined the Annual Labor Day Bridge Walk, traveling south along the five mile Mackinac Bridge, which towers 200 feet above the Mackinaw Straits, connecting the Upper and Lower Peninsula.

Seriously dedicated to NADF in her volunteer position of raising funds for NADF, Heather recognized an opportunity in her and her husband's walk. The generous couple raised an awesome \$2,006.00 toward NADF's goals of education, support, research and a cure for chronic adrenal disease. Thank you so much, Heather and Dave!

As a follow up, Heather reported, "...the bridge walk was perfect, weatherwise and otherwise. We had a great time..."

Heather also shared that she had signed up for a 5K race. She wrote, "The 5K that I'll be running next Thursday (Sept 21) is a marathon for me! I'm in awe of Dusty and Teresa!"

On September 23rd, Heather generously shared, "I told you I'd let you know about my 5K, so here's the wrap-up: I *did* finish, but I walked quite a bit of it, and it was my slowest time ever. Yet, I'm still pleased.

Monday my endo and I had changed my steroid from cortisone acetate to prednisone, and my body did NOT like it! By Tuesday afternoon I was lethargic, had achy pains in every joint, and was nauseated even after I doubled the dose. When I spoke with my doc on Tuesday evening, we agreed that I'd be in the emergency room that night if I didn't go ahead and load up with some cortisone, which I did. Wednesday I went back to my usual schedule of cortisone acetate, but I still didn't feel well.

By Thursday I was feeling much better and decided I could probably walk the 5K. I did a combo of running and walking, and ended up with the phenomenally slow time of 36 minutes. But I finished, and I wasn't last! :) And I was most likely the only person to participate without the function of several important endocrine glands. So 36 minutes was my own personal victory.

It's been a long time since I did an organized race, and I really enjoyed it. I look forward to doing more, and improving each time."

Congratulations, Heather!

TERESA WALLIN

Teresa Wallin ran the New York City Marathon in 2002 (featured in NADF News® VOL. XVII, No's. 2, 3 & 4 • 2002).

Following that wondrous feat, Teresa competed in sprinttriathlons and bicycle tours, but was soon sidelined with a diagnosis of fibromyalgia. She also gave birth to a healthy baby boy.

Teresa, like the Phoenix, rose from the ashes, and entered the New York City Marathon in November of this year.

She shared, "...I'm back, still struggling — but strong."

Teresa will also be running in the Disney World Marathon in January of 2007.

BOISE CITY OF TREES MARATHON

On November 5th, Dusty Hardman ran another marathon - the Boise City of Trees Marathon - with another Addisonian, NADF member Linda Ambard. (Dusty was able to display the NADF banner at the race.)

LINDA AMBARD

Even though she now lives in Colorado, Linda claims Idaho as home. She has entered the Boise Marathon before, and actually holds the record on the old course.

But...that was all before chronic disease struck. Linda shared, "I qualified numerous times, in every marathon I ran, BEFORE Addison's. It isn't so easy now, but I am extremely close to my qualifying time." "...this is my year to finally acknowledge that this is something I will have to get beyond (I've dealt with this insipid disease since 1997). I am stronger and healthier than I have been in a long

time!" "I have slowed down a lot since Addison's Disease, but I am trying to define my life the way I want to live it!"

Linda hopes, through running the Boise Marathon, she will qualify for the Boston Marathon

DEBORAH STANTON

Long Island NADF member Deborah Stanton expressed appreciation for news of the marvelous accomplishments of her fellow Addisonians. She wrote, "It helps us have hope when we see others who are managing to find energy to do the things we enjoy. I hope to be able to send an encouraging report to share with others eventually from my horseback riding adventures as an Addisonian."

On the day Deborah was diagnosed with Addison's disease, her four year old chestnut thoroughbred filly collapsed with Equine Protozoal Myeloencephalitis (EPM) (a protozoa that attacks the brain and nervous system of young horses). Deborah envisioned getting well along with her fellow patient, hoping the recovering youngster would blossom into her next event horse.

On the day that I corresponded with Deborah about her plans, she related that she had been involved in an accident with her filly.

Deborah also owns a 24 year old former event horse mare. She often starts out by riding the mare, while leading the filly with a rope, hoping to tire the frisky youngster out a bit before getting on her back.

That day, Deborah tried riding the filly first, while leading the old timer. When she got to an open field, and tried to turn, the lead line hit the filly's rear end, triggering explosive bucking.

Deborah might have been able to ride out the filly's exuberance, but the lead rope had somehow gotten across her throat, and the mare, feeling the need to go her own way, pulled Deborah off from behind!

Thankfully, Deborah was not seriously hurt by her fall. "No Addison's problems...just cuts and bruises", she assured.

Thank goodness! Be careful Deborah!

Deborah shared that the toughest part of the experience was having to repeatedly explain to her art students the rope burn around her neck.

Later she related, "The filly tried to go bucking bronco again last night, but I stayed on! And today went smoothly. Whew.!"

Be safe Deborah, and best of luck with your frisky filly.

JIM MITCHELL

Jim Mitchell has Addison's disease, and lives in Pennsylvania with his wife and two daughters.

Jim wrote "...I did (the Downingtown "Good Neighbor" day festivities 5K run) in 22 minutes and some change. It was a good run.

I'm still playing soccer despite the occasional minor injuries. I'm feeling fit and I finally have an endocrinologist who is in tune with what I want to accomplish athletically. I even told all the guys that I play soccer with that if I ever got knocked out (which is unlikely) that they should just dial 911 without hesitating.

Hopefully they won't treat me any differently, which I don't think they will.

It is such a joy to be competing and playing. I feel like I've got a new lease on life..."

Way to go, Jim! Thank you for sharing your story with us.

From NADF News®, VOL. XXI, No. 4 • 2006

NADF SPORTING NEWS

LINDA AMBARD RUNS THE LAS VEGAS MARATHON

A month before the race, Linda shared, "...I hope that it doesn't rain! Though it won't be half as much fun as running with Dusty in Boise, this will probably be my last chance to qualify for Boston this year. I am a little concerned about pushing myself this hard in such a short time span. I haven't even completely recovered from Boise yet.

I appreciate your thoughts and encouragement!

Linda Ambard"

On Sunday, December 10th, NADF member and Addisonian Linda Ambard ran in the "New Las Vegas Marathon".

After the race, Linda shared, "Well, I didn't quite qualify for the Boston Marathon with my latest effort in Las Vegas. I did, however, run a great race with negative splits. I ran the last thirteen miles in one hour, 53 minutes.

Unfortunately, the first half was much slower. 16,000 plus runners, to include walkers, half marathoners, and wheel chairs started together. This created a horrible bottle neck of runners. Until the 10 mile mark where we split from the half marathon group, I was constantly behind large groups of slower runners or walkers.

To add to my woes, I had hydrated well on Saturday. Unfortunately, my kidneys flushed water out six times in the first thirteen miles. Six times at a minimum of a one minute pause in running did not help matters. I ended with a 4:10,

SO....I am going to look for another marathon in Feb or March.

I am feeling really tired this week. Maybe this has something to do with how fast I ran the second half. I am struggling with abdominal problems and severe fatigue.

Yes, I am taking time off of running (at least two weeks).

I am so grateful for all of the e-mails and support that you have all given me.

Linda Ambard”

Congratulations to Linda on her awesome accomplishment!

(To interact with Linda and offer her your thoughts and personal congratulations, she can be e-mailed at ambardpl@msn.com)

From NADF News®, VOL. XXII, No. 2 • 2007

ATHLETES FOR AWARENESS

August 4th, 2007 marked an unprecedented event in NADF's history.

Addisonian Super-Athlete Dusty Hardman was undergoing grueling training again, this time for the 140.6 mile Guerneville, California Vineman Triathlon.

The NADF affiliated NorCal Addison's Disease Support Group saw an opportunity to work with Dusty to help her raise money for NADF and support for adrenal patients nationwide. NADF Publicity Director Virginia Perry and NorCal Addison's Support Group Co-Leader Trice Roberts tirelessly sent out press releases, created official forms, arranged housing and travel for volunteers; basically worked very hard to make Dusty's fundraiser a success.

We also want to thank NADF Support Group Coordinator Pam Robbins for the vital assistance she lent to the fund raising effort.

Go Dusty, Go! The Story of Dusty Hardman

Having lived through twelve long winters in Teton Valley, Idaho, Dusty Hardman has learned the value of athletic competition. With nine months of cold, snow and ice, “you had to do something to keep you going,” she says.

But in 2001, Addison’s Disease, a rare, life-threatening but treatable illness caused by insufficient adrenal gland hormone production, suddenly sidelined this aggressive downhill mountain biking competitor.

Suffering from exhaustion, nausea, chest pain and low blood pressure, Dusty spent eight months going from doctor to doctor without a diagnosis, and ultimately was told she was simply depressed.

After doing her own research and writing a paper summarizing her findings, Dusty finally convinced her doctor to prescribe medication for Addison’s Disease, “and I’ve never looked back,” she says.

Since then, Dusty’s health has improved at a slow but steady climb, and her competitive spirit has soared. Over the past five years, she’s run three marathons in Wyoming, Idaho and Colorado, with increasingly better finish times.

“With a 4,000-foot elevation gain, the Teton Races in Idaho were tough,” Dusty says.

But now she has stepped up to an even greater challenge: the Vineman Triathlon in California this August, with a 2.4-mile swim, 112-mile bike ride, and 26.2-mile run.

And she’s combined her love of athletic competition with a new passion: raising funds for the National Adrenal Diseases Foundation (NADF). “With a rare disease like Addison’s, people can die before diagnosis,” she explains. “Yet once treatment begins, most patients have a normal life expectancy. NADF is the only organization that educates the medical community about this disease and offers support and information to patients and their families.”

Along with serving as leader for NADF’s Idaho, Montana, and Wyoming patient support groups, last year Dusty raised close to \$1,000 for NADF during the Teton races.

Now you can help her raise even more by making a 100% tax-deductible pledge of “Dusty Bucks” for her Vineman race.

Dusty’s next steps after Vineman? She’s shooting for a 50-mile trail run in Wyoming and has entered the lottery for the New York Marathon.

With a life-threatening illness, does she ever get nervous about running a marathon? “Listen,” she says. “I train by myself in Idaho and Wyoming backcountry, with bears and moose to worry about. A marathon is a piece of cake.”

To keep up with Dusty’s accomplishments, go to: www.addisonssupport.com

OTHER ADDISONIAN ATHLETES IN THE NEWS

Jim Mitchell

“My official time was 23:55. I placed 172nd out of 786 runners. This time was about a minute slower than my pace last year, but I’ll blame that on a nasty head cold I got a few days before the race.”

Way to go, Jim! Congratulations!

BRIARGATE MARATHON RUNNER AN INSPIRATION

BY GAIL HARRISON

From: The Woodmen Edition, June 29, 2007, Volume XV, Number 26
(reprinted using the Fair Use Act)

Linda Ambard

Ten years ago, Linda Ambard ran a marathon in Frankfurt, Germany, and did well until the fifteenth mile. From then on she faltered and by the end of the race, she was so ill she couldn’t remember her last name.

For the next two years, she underwent numerous tests and with undiagnosed symptoms of severe tremors, drastic weight loss, dangerously low blood pressure that was affecting her heart, and incohesive thoughts, she didn’t understand what was happening and feared she might be dying.

She persisted in running when she could, even during that time.

Finally, after two years of debilitating illness, she learned she had Addison's Disease. She learned that she had had an acute Addisonian crisis during the Frankfurt marathon.

She began her battle to regain her health.

Before developing Addison's, Ambard ran during four pregnancies.

During the fifth pregnancy, she experienced problems with pre-term labor, so she swam daily.

Taking cortisol and fludrocortisone to compensate for her adrenal system's failure to produce those hormones enabled her to resume a normal life—as long as she trains smart and faithfully takes the medications. “Now,” says Ambard, “I am very healthy and very much plan to live to a very old age, running!”

At the age of 15, Ambard, a student at a small private school in Idaho, was shy and overweight. Accepting a challenge to go out for cross-country, she discovered her niche and was off and running. In high school and at Idaho State University, which she attended on a running scholarship, she achieved All-American distinction.

Her first marathon, an easy win, was accomplished at 16.

Through the years Ambard did triathlons and marathons and won many races. Though she always qualified for the Boston Marathon, she never got there because she was either in college, or later after marriage, her Air Force husband was deployed, or she was pregnant or they simply didn't have the financial resources for a trip to Boston.

But she kept the dream alive and this year she ran the Boston 2007.

Her time was not the sharp 2:50 hours she once enjoyed, but a 4:00. However, that time is very satisfying to her, not because of her present age of 46, but because she accomplished it despite Addison's.

According to Ambard, there are five registered marathoners nationwide with Addison's disease.

A major issue with Addison's is the body's failure to retain electrolytes, which can be life threatening.

Ambard says, “The first thing my endocrinologist told me was that I needed to learn to pace myself. He also told me that marathons would tax my body too much.

At the time, I had five children at home, aged 12 and under. However, running was, and still is, my selfish time. It is my time away from the everyday demands.

I'm teaching full time at Falcon High School and teach swimming at the Brairgate YMCA.

Running is as much who I am as anything else. I love being outside, the runner's high, and the fact that no one can bother me when I run (laugh.) The phone doesn't ring when I'm running.

It took six years to get her health stabilized to the point it is now. She ran 10 marathons from April

2006 through May 2007 and has three more on the calendar before the end of this year.

Six years ago, she began special medications and a careful regimen of physical training. She pays attention to restrictions that can cause severe problems. She can't run in heat over 65 degrees. And she is still discovering which amount of medication works best for her.

Ambard says, "This past year, my running clicked again. No, I will never be anywhere near the top of my age group, but I am okay with that. I fell in love with running again. I entered marathon after marathon; in the process, I became part of an elite marathon group – the Marathon Maniacs. I ran 10 marathons in a calendar year. I ran in Idaho, Washington, Nevada, Louisiana, Colorado, Oregon, and, of course Massachusetts. I qualified for Boston at the Mardi Gras Marathon in New Orleans."

Her next three races are in Oregon, Alabama and Arizona.

Ambard is exuberant about her experience in Boston. Even in atrocious weather, she loved running with the caliber of the athletes in the race, loved the excitement of the crowds, and says she zoomed up the hills in Boston because of her training in Colorado. (This year's Pikes Peak Ascent will be her fifth.)

When she crossed the finish line in Boston and received her medal, she couldn't stop smiling.

The Ambards moved to Briargate five years ago. Her husband, Phil, is active duty Air Force. Their children are: Patrick (24, USAFA graduate, medical school), Joshua (23, Army nursing program), Emily (21, a 2007 USAFA graduate), Alex and Tiger "Timothy" (both juniors at Liberty).

Linda Ambard is an inspiration. She shares her philosophy, "I aspire to encourage people to find an activity that they love and to stick to it. I may come to the day when I can't run, but then I will swim or do something else. Though we all have battles that we must fight in our daily lives, I am not ready to stop. I am fighting the fight. I am finishing the race and I am keeping the faith."

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

ATHLETES FOR AWARENESS

From Dusty Hardman on her races after Vineman:

Teton Races, 50 miles, Alta, Wyoming - September 1, 2007

Horseshoe Challenge, 20 kilometers, Driggs, ID - September 15, 2007

New York City Marathon, 26.2 miles, New York, NY - November 4, 2007.

"Why a 50 you might ask? I'm in shape and I feel good, it's close (about 20 miles from here). I've never run an Ultra before. It's on my home turf and the views are spectacular! Doing the 50 is yet another way to test my limits and see what my body is capable of. Besides, I can eat a lot if I run 50 miles, right?"

From NADF News®, VOL. XXIII, No. 1 • 2008, front page

...Addisonian Marathoner Linda Ambard shared with NADF that she is gearing-up to run several events this year, including the Boston Marathon. If you live in the area of any of Linda's listed marathons, feel free to attend the event to show your support. If you let NADF know of your plans, we can ship an NADF banner or banners for you to display at the finish line, or along the marathon route.

Linda's event dates and locations are:

Monday, April 21, 2008 - Boston Marathon
<http://www.bostonmarathon.org/BostonMarathon/112thMarathon.asp>

Sunday, June 8, 2008 - 2008 6th Annual Casper
Marathon in Casper, Wyoming
<http://www.runwyoming.com>

Sunday, July 13, 2008 (Linda's 47th birthday!) - 2nd
Annual Missoula Marathon and Half Marathon in Missoula, Montana
<http://www.missoulamarathon.com>

Good luck, Linda!...

From NADF News®, VOL. XXIII, No. 3 • 2008, page 6

ERIC MOSSOP – ADDISONIAN WRESTLER

It's nice to know that I'm not the only one with Addison's that is overcoming the disease to do well in athletics. Just a couple months ago I wrestled in my first competitive tournament since college (and since being diagnosed with Addison's) and came in 2nd place to an athlete who took 5th place in Eastern Nationals, only losing by one point. I look forward to training for next year's tournaments and placing in Nationals myself. Good luck to Linda (Ambard). I was diagnosed a year ago after an Addisonian Crisis left me at 105 lbs after being around 140. I was a "stubborn male" for the most part until then. I put off getting checked out because I was coaching and kept saying that I would get bloodwork done after the season was over. I did go the day after it was over, but a couple days later found myself in the hospital. Ever since I was diagnosed though, I have felt better. It is mildly entertaining having conversations with the wrestlers I coach telling them "yes, the wrestling coach is on steroids – no, they're not anabolic steroids – steroids are bad for you." - Eric Mossop

From NADF News®, VOL. XXVII, No. 2 • 2012, page 3

Dusty's Run for Adrenal Insufficiency

Dusty Hardman, an amazing athlete who also has Addison's Disease, will be running in the, "Last Annual Vol-State Road Race," a 500km foot race across the state of Tennessee. The race is scheduled to run July 12-22 of this year. It will start in Dorena Landing, MO and will end in Castle Rock, GA; a distance of over 300 miles!

Dusty is hoping to raise awareness for people with Addison's Disease, and sets an example of how Addison's is a treatable condition that doesn't have to limit a person's life.

As an Addisonian, Dusty faces a greater challenge than the average competitor. Braving a Tennessee Summer day can be a challenge for anyone with adrenal insufficiency, but Dusty plans to do so while engaging in athletic activity day after day. Her perseverance is a testament to what can be achieved by people who share her illness.

Proceeds from Dusty's run will go towards helping members of Adrenal Insufficiency United (AIU) attend the IAFC Fire- Rescue International Conference in August of this year.

Please visit Dusty Hardman's blog, "Training Because I Can!" at: www.addisonssupport.blogspot.com and Adrenal Insufficiency United's (AIU) website at: <http://aiunited.org/> for more information.

To donate in honor of Dusty's accomplishments, please visit <http://www.aiunited.org/index.php/support-us/dustys-500krace-for-awareness>

From NADF News®, VOL. XXVII, No. 3 • 2012, page 2

Addison's Disease Makes it to the Olympics

Living with Addison's disease is not, strictly speaking, easy. It is a chronic illness that pervades the aspects of a person's life. It is a burden that Addisonians must learn to cope with, and for some this is extremely difficult. It is a victory for these individuals just to reclaim the life they had before they started to experience symptoms. But some Addisonians shoot for a little higher, and try to achieve greater personal victories after the disease starts to press down on them.

Consider Nathan Gafuik: Nathan was the only male gymnast to compete in the London Olympics this year for his country, Canada. Nathan was also an alternate for the Canadian gymnastics team at the Athens Olympics in 2004, and competed four years ago in the Beijing Olympics, making this his third time appearing in his sport's biggest arena.

Nathan was diagnosed with Addison's disease at 15. He is now 27, and a three-time Olympic gymnast.

Before his diagnosis, Nathan was already considered one of Canada's best young gymnasts. The training regimen he went through put his body under stress, and at the onset of his symptoms he looked small and underweight for his age. He vomited at competitions, and would be too exhausted to leave bed afterwards. He had severe cravings for salt, and during the winter he had an unexplained tan.

When he was diagnosed, it seemed Nathan's health and passion for gymnastics were at an impasse. He wanted to continue competing, as his gymnastics career was on the rise. But this would mean putting his body under continued physical and emotional stress that even the average healthy person doesn't go through. Gymnastics routinely requires advanced acrobatic maneuvers performed at high speeds, which is a recipe for disaster if something goes wrong.

Because Addison's disease is so rare, there was no text book way to balance his illness with gymnastics. The two simply have not met before in any record his doctors had as a resource. They weren't sure Nathan could continue competing at all. With support from his parents, coach, and endocrinologists, Nathan tried to keep up with training and competing in gymnastics anyway. But he did so blindly, and there were serious setbacks.

Taking supplements to replace his body's lack of cortisol and aldosterone, Nathan's health seemed to get back on track. However, he had to learn through trial and error how much cortisol he needed. He couldn't follow a consistent regimen because the stress on his body wasn't consistent. He had to take extra cortisol in preparation for competitions, but taking too much made him feel jittery, which could negatively affect his performance.

As Nathan continued to succeed in his sport, he and his parents discovered that the success brought with it greater levels of stress. He needed to travel through different time zones, participate in even more difficult training camps, and was faced with even more challenging competitions. All of these things affected Nathan's ability to monitor his condition, and take the correct amount of supplement.

At the age of 16, Nathan suffered an accident on his best event: the high bar. His neck clipped the bar during his routine, and he ended up falling on his face. Without enough cortisol for his body to cope his blood pressure could drop and send him into a coma. He needed to be rushed to a hospital, but luckily recovered.

Two years later in Russia, Nathan suffered an Addisonian crisis from the stress of traveling internationally. This caused a terrifying ordeal for him and those close to him, as he ended up passing out in the emergency room, and couldn't receive proper treatment from doctors that did not understand his condition. Nathan was flown home, and recovered. His mother, Jo-Ann Munn Gafuik was quoted as saying, "I think that was the worst night of my life."

Through all of this sometimes terrifying trial and error, Nathan eventually learned how to handle his condition so he can compete at his best. When competing at the 2008 Olympics in China his mother recalled that, "I had never seen him compete as comfortably and with as much joy on his face."

At the Olympic games in London, Nathan had to withdraw from all but one event because of a thumb injury. He sadly ended up falling from the high bar during his routine, and failed to qualify for the men's final. Despite this, Nathan Gafuik stands as an example of what is capable for people with Addison's disease. Not just normalcy, but greatness.

From NADF News®, VOL. XXVII, No. 3 • 2012, page 6

500 Kilometers

In the last issue of the NADF News® we ran an article about Dusty Hardman, an adrenal insufficient long distance runner participating in the "Last Annual Vol-State Road Race" to help raise money for Adrenal Insufficiency United (NADF News® Vol. XXVII #2, Dusty's Run for Adrenal Insufficiency).

The "Last Annual Vol-State Road Race" was a 500km (roughly 310 miles) across the state of Tennessee. Well, Dusty did it! She completed her run in 8 days, 11 hours 4 minutes and 47 seconds, and received over \$5,000 in donations for her cause to date.

In order for Dusty to make such a long distance run, she must adhere to a regimen of her required medications in order to constantly supply her body with enough hydrocortisone, fludrocortisone acetate (a.k.a Florinef®), and other supplements over the course of her run. For the first three days, Dusty was taking 5mg of hydrocortisone every hour after her initial morning dose. But, by the third day she realized this still was not enough hydrocortisone to make up for what her body needed, and so she changed to 10mg an hour. That amounts to 100 - 150 mg of hydrocortisone

per day! Because of the heat, she had to also drink roughly two gallons of water a day, and take 2 salt supplements every hour.

On her blog, Dusty accounts for the years of trial and error it has taken to come up with a regimen that allows her to run with her condition. Even with her years of experience in managing it, she had to change her original game plan when she realized her dosage of hydrocortisone was too low.

Dusty's 500km journey isn't just a testament to her physical endurance. It is a testament to her heart.

Congratulations Dusty!

If you would like to make a donation for Dusty's incredible accomplishment, then visit: <https://fundrazr.com/campaigns/2JKs7>

Addisonian Makes 5k Run

We would like to congratulate Addisonian and NADF member Jim Mitchell from Pennsylvania on his successful 5 kilometer run.

From NADF News®, No. 2 • 2013, page 3

What a Person can Accomplish

Over the weekend of January 19th-20th 2013, weightlifting athletes gathered for the Amateur Athletics Union World Powerlifting Championships. Lisa Markland, the Addisonian who has also been leading a petition to the White House to establish an Addison's Disease Awareness Week, attended the Powerlifting Championships for the first time. Not only is Lisa an Addisonian, but she also has Ehlers-Danlos Syndrome (EDS), and incomplete tetraplegia from an accident while she was in the Air Force. This reduces her mobility to the point she needs the assistance of a wheelchair. EDS is a rare genetic condition that affects the connective tissues in the body, resulting in possibly weakened muscles, easily dislocated joints, and fragile organs. Lisa herself experiences torn ligaments regularly. Lisa performed the benchpress and deadlift for the Powerlifting Championships, but first had to transfer from her wheelchair to do so.

Lisa deadlifted 99 pounds, and set an American and world record in her division of the military master's single-lift bench, by benchpressing 75 pounds.

If setting a world record, in your first ever championship meet, in your athletic competition of choice, while suffering from multiple physically limiting medical conditions isn't the kind of achievement that demonstrates the power of a human being's determination, then the very definition of achievement should be evaluated.

Lisa also participates in marathon foot races as a wheelchair entrant, and while she enjoys participating despite her conditions, she still strives to win.

An Athletic Update from the Amazing Lisa Markland

I keep forgetting to let you know that while I used to bicycle distance (even a century/100 mile ride in

a day!)... I haven't done that since 1988 when I sustained a pretty serious spinal injury, which is why I turned to handcycling.

The main things I continued to do as a "disabled" athlete include:

- handcycle races (up to marathon distance)
- powerlifting (world and national champion, not adaptive)
- target shooting (up to the Olympic/Paralympic level for Team USA)
- fencing (recreational but not adaptive)

... and for years had also done:

- men's DIII wheelchair basketball (coached and played up to a national level)

I also competed annually in about 1/2 dozen other sports but these are the main ones I really excelled at. Prior to becoming "disabled" (far prior to AI), I was also a national medalist in Tae Kwon Do, training about 30 hours/week (crazy!). Can you tell I love sports?!? :)

Hope this will help and will help others as well!

Thanks for including me, btw. I'm truly honored!

From NADF News®, VOL. XXVIII, No. 4 • 2013

Addisonian Completes Portland Marathon

NADF would like to congratulate Natalia Martin for completing the Portland Marathon on October 6, 2013. Natalia was diagnosed with Addison's disease only 16 months before she took part in the grueling athletic event. Natalia's finishing time was good enough to qualify her for the Boston Marathon, though she is not planning on attending.

Natalia's achievement is just one of a few she plans on undertaking. She is planning on competing in no less than four marathons in 2014, including next year's Portland Marathon on October 5, 2014.

Q & A with Dr. Margulies, not yet printed in the NADF News

Q. "Dear Dr. Margulies, I am a 46 year old male who was diagnosed with Primary Addison's Disease in January 1994. I am presently taking a maintenance dose of 35 mg of hydrocortisone as well as .05 mg Florinef a day. I have noticed by reading the Newsletter that there are two women who run races. One runs in super elite races and the other in marathons. I have been running 5K races for the past three years. I have not heard of any men who are into sporting events such as running who also have addison's disease. I feel and do very well in these races. I take extra steroids and do carb loading prior to as well as on race day. I am wondering if there is something different with my Addison's that allows me to be able to participate in these running activities (I also play soccer in an over 35 league). Could it be anything with my hormones, genes, or metabolism that allows me to do this and why can't more Addisonians participate in sports. Thank you for your time. Regards,"

A. "I am delighted that you run in races and participate in sports. Basically, it means you are in good general health, with the maintenance of your adrenal steroid replacement keeping you in balance. There is nothing else special about your situation. Most otherwise healthy Addisonians can do whatever they want physically and professionally. We often highlight Addisonians who do physically challenging activities to show our membership that they should not feel limited by their disease. Obviously, not everyone can do this. Many people with Addison's disease are debilitated by the presence of other diseases or complications from years of inadequate treatment. Some just never feel well despite appropriate medications. Good luck and continued good health.

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

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

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