



Sharing

Should you tell your employer?

In the Spring issue of COAST News, we posed the question, "Should you tell your employer you have Addison's?" We heard from a few of you, with mixed opinions.

"No," wrote one member who wishes to remain anonymous. "Especially in this economy, businesses are looking for ways to cut back on expenses, and if they think they have someone who might cause their insurance rates to go up, or who might take too much sick leave, they'll find some other reason to get rid of you."

Kim Donato disagrees. "My employer knows because I was diagnosed while working here," she writes. "They were very supportive through years of being nearly disabled by Fibromyalgia pain and then 7 months of misery prior to crisis/diagnosis. I am very lucky to work with such caring people."

Kim, an HR Administrator, also thinks it's important for her employer and co-workers to know. "They understand I am more susceptible to germs/illness and they stay away from me when they are sick."

Some experts think you should explain your condition to your boss instead of trying to conceal it. Otherwise, you might give the impression that you simply don't care about your work, or are inept. Addison's is included in the Family and Medical Leave Act (FMLA), which provides up to 12 weeks of unpaid leave if you are unable to work because of a serious health condition. For more information about FMLA, go to: <http://www.dol.gov/dol/topic/benefits-leave/fmla.htm>.

The Americans with Disabilities Act (ADA) prohibits employers from dismissing or failing to hire those who are chronically ill on the basis of that disability "if they are able to do the job with reasonable accommodation." But interpretation of "reasonable accommodation" is left up to the boss, and that might not be the same interpretation as the employee's.

The US Labor Department's Job Accommodation Network's website offers excellent advice for those considering whether or not to divulge their condition at work.

Please see "Should you tell?" on page 3

Everyone's Welcome!

Fall Meeting slated for October 11

The Fall COAST meeting will be held from 1 to 3 pm on

Saturday, October 11, 2008

First Church of Christ

206 W Dayton-Yellow Springs Road

Fairborn

From the north, take I-70 to I-675 south, then take the Dayton-Yellow Springs exit and turn

left toward the city of Fairborn. The Church is on the left after you pass Ironwood Street. If you need further directions, call Marianne at 937-554-6383.

The topic for this meeting is "Addison's Basics." We hope you'll join us for discussion and sharing. We have several newly-diagnosed patients who are eager to learn from those more experienced with adrenal insufficiency.

As always, bring along friends and family members, and a small snack to share.

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The Central Ohio Addison's Support Team does not engage in the practice of medicine. COAST is not a medical authority, nor does it claim to have medical knowledge. The content of this newsletter is intended as information and sharing of experience only, and is not in any way a substitute for proper and expert medical care. In all cases, COAST recommends that you consult your own doctor regarding any course of treatment or medication.

Feeling a little "Addisonian"? Having an Addison's Day?

Did you notice that there was no summer edition of COAST News? I simply didn't have time, and decided that the added stress of trying to write a newsletter might push me over the proverbial "Addison's Cliff."

I was trying to successfully finish up a full-time schedule of classes at The Ohio State University, was tutoring math and hoping those students also did well on their exams, and was leading a week-long birdwatching excursion to South Texas, all while trying to keep up with the things everyone does on a daily basis. So I took my own advice. I decided that the world could live without hearing from me, and skipped writing a newsletter.

After calling and emailing a few of COAST's "core group", we decided that attendance would be so small that we should cancel the July meeting. I sent out a brief email to the COAST membership to let everyone know of the cancellation. I neglected to send post-cards to those who don't have Internet access, and I apologize to those who weren't notified.

Evidently, everyone else was just as busy as I was! Just one member called and asked about the missing newsletter and the cancelled meeting.

Not to let myself off the hook, but I think I did the right thing for myself. Those of us with Addison's need to learn to say no and perhaps let things slide a bit—far more often than we do. Whether it is something

we really want to do—meet a friend for lunch, or go for a brisk walk around the neighborhood—or something that is a chore, we must learn to evaluate how well we feel at that moment, and decide if it is our best interests to carry through with our commitments.

Writing these words goes against everything I believe in. I was voted the "Most Dependable" person in my high school class. In my volunteer positions in the com-

munity, I am recognized as a perfectionist who gets the job done, on time. I'm never late, not even by a minute or two. But maybe that's not the best thing for me anymore.

The next time I'm feeling a little "Addisonian" (if you have Addison's, you **know** what I mean!) I will consciously stop and take care of myself. Do I need to bump my steroid dose a smidge? Take a nap? Eat

a salty snack? Cancel a planned activity? Leave a task undone? Have a pizza and salad delivered for dinner? Ask for help?

The best thing we can do is take care of ourselves to stay as healthy as possible. After all, if I don't take care of myself, who will?

Here's to Good Health!

Heather

If you don't take care of yourself, who will?

Research

Meds three times a day might be better than twice daily

A recent study in the UK indicates that taking hydrocortisone three times a day might be superior to the standard twice. The aim of the study was to assess hydrocortisone replacement therapy in patients with adrenal insufficiency, by correlating hydrocortisone regimens and doses to that of serum and urine cortisol levels.

The researchers studied the case notes of 83 patients whose records contained the results of at least one valid hydrocortisone day curve and 24-hour free urine cortisol level. Twenty-seven patients were on twice daily, and 56 were on thrice daily regimen.

Optimal hydrocortisone replacement therapy was defined as that dose which achieved 24-hour urine free cortisol, and morning, afternoon, and evening serum cortisol levels within normal reference range.

There were 32 (50%) patients on thrice-daily hydrocortisone regimen who achieved optimum cortisol levels at all times as compared

to only 4 (15%) on twice daily regimen.

Optimal cortisol replacement was achieved in 78% and 75% patients on hydrocortisone 10+5+5 mg, and 10+10+5 mg, respectively; other thrice daily regimens did not achieve optimal replacement.

The average serum cortisol levels at 1 p.m. and 5 p.m. were significantly lower in patients on twice daily as compared to thrice daily regimen, however there was no significant difference in the average serum cortisol levels of the two regimens at all other times.

The 24 hour urine cortisol levels were within reference range for patients on total daily cortisol dose between 15 and 25 mg, however, the levels were low in those receiving total cortisol dose of 10 mg/day, and high in patients receiving total daily dose greater than 25 mg.

The researchers concluded that a thrice

daily hydrocortisone regimen is superior to twice-daily regimen, and the appropriate recommended total daily hydrocortisone dose is 15 to 25 mg/day, in three divided doses. The 24 hour urine cortisol profile is a reasonable measure for assessment of the total daily dose, but not the frequency or the regimen of cortisol replacement.

Source: Munish Batra, Ammar Tariq, and Abu Ahmed, April 2008; Assessment of optimum hydrocortisone replacement therapy in patients with adrenal insufficiency. Presented at the Society for Endocrinology BES 2008; Endocrine Abstracts (2008) 15 P300.

For more abstracts of recent endocrine research, search at www.endocrine-abstracts.org. Search on "adrenal insufficiency" as well as "Addison's Disease" and any other topics of interest, such as associated conditions or medications.

Should you tell? continued

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Kim Donato disagrees. “My employer knows because I was diagnosed while working here,” she writes. “They were very supportive through years of being nearly disabled by Fibromyalgia pain and then 7 months of misery prior to crisis/diagnosis. I am very lucky to work with such caring people.”

Kim, an HR Administrator, also thinks it’s important for her employer and co-workers to know. “They understand I am more susceptible to germs/illness and they stay away from me when they are sick.” Some experts think you should explain your condition to your boss instead of trying to conceal it. Otherwise, you might give the impression that you simply don’t care about your work, or are inept. Addison’s is in-

She’s glad, continued

I have doctor appointments, call in sick, or need to work from home. They are a small company and can be more flexible for those with health problems, babysitter issues, etc

They encourage me to leave a supply of my meds at work so I will always have them, and if I ever forget some and have to run home to get them, they will even have one of the young trainees to drive me home.

Overall, telling my bosses WAS the best thing for me to do. It was also very necessary, since I was sick so often, and they were genuinely concerned for my welfare.

I always give them credit for standing by me and supporting me, and doing all they can to keep me working and taking care of myself.

One person’s story

She’s glad her employer knows

By Kathy Krantz, New Jersey

I work for a small architectural firm as an administrative assistant. I began working for them in January, 2001. At that time, I was young (36), healthy, active and vital. For the first year or two with the company, I worked 45 to 60 hours each week, and also worked part-time from home doing book-keeping for a store. This meant I was working about 75 to 80 hours per week, plus dating and socializing.

When they hired me I told them I had severe asthma, as I had to wear a Medic Alert bracelet. I would usually have several severe attacks each summer. I figured it was better to honest up front than get settled in and possibly be fired later on for not telling them.

In January, 2004, I came down with a bad cold. The “cold” turned into a “virus” which spawned a serious asthma attack which spiraled out of control for the next month or so. I would start to regain my strength and get better, only to have one serious asthma attack after another. The local ER doc finally suggested I see a pulmonologist. Well, as all of you with Addison’s know, thus began my long, long journey down the road to diagnosis.

My diagnosis was VERY hard to come by and, unfortunately, quite dramatic in nature. Many, many times I got very sick at work, called in a lot more than normal, etc. There was no hiding the fact that there was something desperately wrong! I basically looked like the “walking dead” for the 6-9 months that led up to my diagnosis, and for about the first year after my diagnosis. All this time, I had to keep working; I am unmarried and live alone. I became weak, pale, and my skin began to take on a light gray consistency.

Finally, after just about passing out at work and having to be carried home, I had to explain to them that I had been diagnosed with “Addison’s Disease”, or “Secondary Adrenal Insufficiency.” This was NOT easy to explain to people with absolutely no medical background, especially since my Endo was still in denial herself, and had only grudgingly given me the Cortrosyn Stim test after my pulmonologist sent me back to her for the third time and asked her point blank, “Are you waiting until she’s DEAD?”

Thank God for my pulmonologist! Had it not been for his knowledge and understanding, I don’t know if I would have even made it through. All of the information that I got at that time was from the Internet.. My pulmo admitted that he was not fully educated about it, but at least he had seen it before. He knew what to test for and to get me started on replacement steroids. It took several attempts to find the best steroid and dosage for me. Every time my endo would try to switch me to prednisone or taper my dosage, I would get very sick. I am still maintained on 30 mg, hydrocortisone daily—20 in the morning, and 10 in the afternoon.

I had to be very forceful with my endo about NOT attempting to taper anymore, because I cannot work if I am constantly sick and miserable. I have to keep working for a living, and in order to keep working, I have to be reasonably healthy.

In 2005 I contracted Lyme Disease and became very sick again. This, too, took a long time to properly diagnose, and I was forced to go on Short Term Disability until we found the cause. Once I was diagnosed and started the antibiotics, I began improving right away. Finally, in August, 2005, I went back to work. I actually had some color to my cheeks, and I was eventually able to go back to working 35 to 40-hour weeks.

My bosses were thrilled just to have me back at work and no longer a liability (passing out, throwing up, etc.). Since then they have allowed me to cut back to 30 hours a week, and let me work from home on the days when I am too ill to go into the office. They also bought me Voice Recognition Software to use after Rheumatoid Arthritis rendered my right hand virtually useless, and a special computer mouse designed for those with severe arthritis.

They have been very compassionate, even though I know they do not fully understand my illness. They do their best to work with me when . (Story continues at left. Please see “She’s Glad”)

ADA Amendments Act Passes both House and Senate

The Americans with Disabilities Act (ADA) Amendments Act (S. 3406) has passed in both the U.S. Senate and the House of Representatives. This is a major victory for people with Addison's Disease and other chronic illnesses. This bill ensures that people will be judged on their ability to do their job, and not be punished for how well their condition is managed.

Since there were differences between the House and Senate bill, the next step will be for the House to vote on the ADA Amendments Act next week. It will then go to President Bush to be signed into law. This was occurring as COAST News went to press. To check on the progress of this important piece of legislation, go to: <http://www.govtrack.us/congress/bill.xpd?bill=s110-3406>.

Gender, time of day affect response to vaccinations

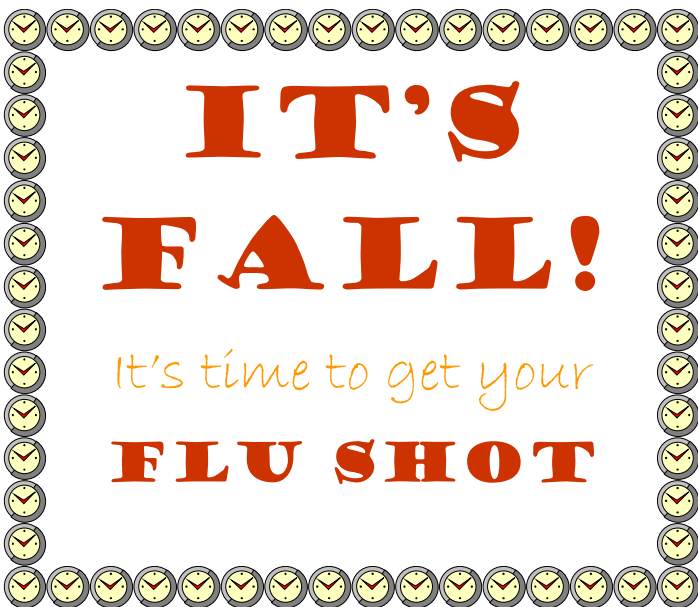
A study in the United Kingdom indicates that the time of day you receive a vaccination might affect its effectiveness. Led by Anna Phillips of the University of Birmingham, researchers assessed the response to a hepatitis A vaccine in healthy young adults and also examined responses to the annual influenza vaccine in older community-based adults.

In the first study, participants consisted of 75 University of Birmingham students who were vaccinated with the hepatitis A vaccine during a morning session (1 am to 12 noon) or early evening session (4 to 6 pm). In the second study, 90 older adults also received their annual influenza vaccination in the morning between 8 and 11 am. or in the afternoon between 1 and 4 pm.

Men vaccinated in the morning showed the strongest immune response. Almost twice as many men showed a twofold increase in antibody response when vaccinated in the morning as opposed to the afternoon.

"If we can replicate these findings in a randomized controlled trial, there would be implications for the time of day for vaccinating those at risk," the authors conclude. "Adults could be vaccinated at a specific time of day to increase their protection against the flu."

The Center for Disease Control stresses that people with chronic diseases such as Addison's should have their flu shots in the fall in order to have influenza-specific antibodies before the brunt of the flu season hits in winter and early spring.



In Memoriam

It's with great sadness that we report the passing of three people who made a difference.

Bob Shierry passed away on September 9, 2008. Bob, a retired civil engineer, was an active community volunteer in the Champaign, IL area, and he led the Central Illinois Addison's Support Group. Our condolences go out to his wife, Helen.

Christy Lapi, an active volunteer with Canadian Addison's Society, passed away April 6, 2008. Our condolences go to Christy's daughters and other family members.

J. Patrick Rooney died September 15, 2008 in Indianapolis. Mr. Rooney was not active in the adrenal disease community, but was the founder of the Fairness Foundation, which works to help low-income Americans acquire health care.

Yes, COAST still needs your help!

COAST can be a successful support group only if everyone pitches in and does what they can to make it work. If you or someone in your family can make a few phone calls to arrange speakers for our 2009 meetings, more Addisonians will come to the meeting, and everyone will benefit. We have ideas for speakers—we just need someone to follow up and make the phone calls. If you'd like to do this to help support others with Addison's Disease, let Betsey know (614-854-0926; Heb30@aol.com).

Lucky Country Aussie Style Soft Gourmet Licorice recalled

Lucky Country Inc. of Lincolnton, NC is recalling all of its natural black licorice products due to elevated levels of lead. We are reporting this in COAST News because many people with adrenal insufficiency, especially those who are under-replacing adrenal steroids, crave licorice. Natural licorice bolsters mineralocorticoid levels because it contains glycyrrhizinic acid, an inhibitor of steroid breakdown. In historical times, before the advent of the replacement medications used today, it was used as a remedy for Addison's Disease. (**Note: Licorice is NOT a viable treatment for adrenal insufficiency!**) We are includ-

ing this recall notice because several people have brought licorice to meetings, and other have commented that they still crave it.) The recalled licorice was sold in California, Colorado, Connecticut, Florida, Georgia, Hawaii, Iowa, Illinois, Indiana, Massachusetts, Minnesota, New Hampshire, Pennsylvania, Utah, Virginia and Washington State. Tests performed by the California Department of Public Health and the FDA showed that Lucky Country Aussie Style Soft Gourmet Licorice Black (All Natural) in 1.5 lb bags contained a lead level exceeding the level permitted in candy. Because of this finding,

Lucky Country is voluntarily recalling all of its black licorice from the market. In addition to the 1.5 pound bags, Lucky Country also manufactures this natural black licorice product in 6 oz. and 3 pound bags, and in a 1 pound tub. Consumers are advised to check to see if they have this product in their possession and should either dispose of it or return it to their retail outlet for a full refund. Consumers with questions may contact the company at customerservice@lucky-country.com, or 1-828-428-8313 during business hours.

Thanks to those who make COAST happen!

The Central Ohio Addison's Support Team (COAST) was founded in the autumn of 2004. A support group of the National Adrenal Diseases Foundation (NADF), we are a group of people who want to make life better for those with Addison's Disease.

COAST does not engage in the practice of medicine. COAST is not a medical authority, nor does it claim to have medical knowledge. In all cases, COAST recommends consulting your doctor regarding treatment.

Our goals are:

- To provide a caring network to support people with Addison's Disease.
- To supply up-to-date information to people with Addison's Disease
- To help educate health professionals to have a greater awareness of Addison's Diseases, and
- To make the general public aware of Addison's Disease.

We meet four times a year, always on the second Saturday of the month. Upcoming meetings are:

October 11 - Columbus

January 10, 2009 - Pataskala

April 11 and July 11, 2009, locations to be announced.

Here are the volunteers who make COAST possible:

Chair—Betsey Greenwood-
HEB30@aol.com
614-854-0926

New Contacts—Marianne Kowalchuk
MKowalchuk@mac.com
937-554-6383

COAST News Editor—Heather Nagy
COAST@columbus.rr.com
740-964-6306

Copies and Dist. Diane Koontz
diane.koontz@kingthompson.com

We'd like to hear from you if you have an idea for a program or speakers (whether you wish to arrange for this or not), or have an idea for an article in this newsletter. We are

also looking for people to share their Addison's experiences in this newsletter.

If you are a member who lives too far away to attend meetings, consider finding a community meeting place (not a private home) and inviting us to visit your community! Before you make arrangements, though, please contact Betsey or Heather to make sure we don't have two people planning for the same meeting.

Thanks to these generous people who contributed to this issue of COAST News:

Kim Donato

Dusty Hardman

Kathy Krantz

Sarah Nagy

Elizabeth Wathen

Anonymous contributors

The deadline for the next issue is December 1, 2008.

Refrigerate your Florinef

According to Bristol-Meyers Squibb, Florinef should be refrigerated. There has been no change in the formulation, but new data indicates that it will remain stable for 24 months in the refrigerator, as compared to just 30 days or more at room temperature.

A March 2008 letter to US pharmacists advises that fludrocortisone acetate should be shipped and stored at 4 degrees Celsius, or 39 degrees Fahrenheit. This is a change from the "tightly capped vial at room temperature" standard previously in use.

Although Bristol-Meyers Squibb manufactures only brand-name Florinef, it is assumed that the new storage standards should be used for generic fludrocortisone acetate tablets. There have been no alerts for hydrocortisone and other replacement steroids, but you may wish to ask your pharmacist about these.

Because Florinef will remain stable at room temperature for 30 days or more, there should be no trouble taking the unrefrigerated pills along on vacations.

If you've been getting room temperature pills from your pharmacy, talk to them about this change. This information should be typed on every vial of fludrocortisone, and should be mentioned by your pharmacist when you pick up your chilled medication.

For more information about this topic, or to find out



about stability after 30 days at room temperature (or perhaps higher, if you mail-order your meds) contact Squibb at 1-888-550-6060.

If your fridge looks like this, you'll want to clear a dedicated spot for your Florinef!

Research

Study shows DHEA benefits for Addison's Patients

Research carried out in the UK and New Zealand and reported in the February issue of the Journal of Clinical Endocrinology and Metabolism suggests that Addison's patients can benefit from DHEA therapy.

Dehydroepiandrosterone (DHEA) and DHEAS are the major circulating adrenal steroids and substrates for peripheral sex hormone biosynthesis," Dr. Krishna K. Chatterjee wrote. "In Addison's disease, glucocorticoid and mineralocorticoid deficiencies require lifelong replacement, but the associated near-total failure of DHEA synthesis is not typically corrected."

In a double-blind trial of 106 people with Addison's disease (44 males, 62 females), patients received either 50 mg daily of micronized

DHEA or a placebo orally for 12 months, to evaluate its longer-term effects on bone mineral density (BMD), body composition, and cognitive function, together with well-being and fatigue.

Circulating DHEAS and androstenedione rose significantly in both sexes, with testosterone increasing to low normal levels only in females.

DHEA reversed ongoing loss of BMD at the femoral neck but not at other sites; it also enhanced total

lean mass significantly with no change in fat mass.

At the beginning of the study, psychological well-being was evaluated using questionnaires, and was found to be "significantly worse" in

Addison's patients versus the control population. This improved significantly following DHEA treatment. There was no significant benefit of DHEA treatment on fatigue, cognitive or sexual function.

Supraphysiological DHEAS levels were achieved in some older females who experienced mild androgenic side effects. (This has also been reported anecdotally at COAST meetings.)

The research team concluded, "Although further long-term studies of DHEA therapy, with dosage adjustment, are desirable, our results support some beneficial effects of prolonged DHEA treatment in Addison's Disease."

This article was adapted from The Journal of Clinical Endocrinology & Metabolism Vol. 93. No. 2 400-409, under the provisions of the Fair Use Act.

"Our results support some beneficial effects of prolonged DHEA treatment in Addison's Disease."

Artist to make Addison's Quilt

By Dusty Hardman, Idaho (from Dusty's website www.addisonssupport.blogspot.com)

My friend Shelley (who also has Addison's) will be creating one of her lovely quilts to benefit the National Organization for Rare Disorders (NORD) an organization to which the National Adrenal Disease Foundation belongs. (Learn more at www.rarediseases.org.) Shelley will use pieces of clothing donated by those of us with Addison's Disease and other chronic illnesses. Shelley's an incredibly talented artists and quilter. If you have things that are especially associated with you and what you do or enjoy, please consider sending these to be included in Shelley's quilt.

Please send your clothing items and contact information to: Shelley Lerdahl, 501 N. 3rd W., Rigby, Idaho 83442.

After the quilt is finished it will be auctioned and the highest donation bidder will then contribute the amount of their bid to NORD in honor of Shelley Lerdahl. Neither Shelley, nor those participating in its promotion, will receive, accept, or manage any monies. All will go directly to NORD. Both the donor and Shelley will receive acknowledgement of the receipt of the donation.

When the quilt is completed, we will post the details of the donation auction in further detail. I wish to repeat: **You will be bidding to donate directly to NORD.**

Shelley was thinking that it would be neat to have a list that says what the people did included with the quilt, for example:

"Dusty, Addisonian, worn while doing the 50 mile Teton race" or

"Shelley, Addisonian, pants too big—lost 40 pounds."

We look forward to watching Shelley's progress . . . But remember, she needs your clothing to make this happen!

Sharing

What do you do to get fit and stay fit?

By Heather Nagy

We've read in NADF News about people with adrenal disease who complete triathlons, marathons, long distance hikes, and 5K races. They inspire all of us to do all we can to stay fit. Not all Addisonians are going to be able to run a race (of any length), or even walk out to the end of the driveway to get the mail. But as I have spoken to people over the past few years, I've come to realize that everyone wants to be fit.

So I'm calling on everyone who's doing something to get fit or improve their fitness level. Whether it's walking around the neighborhood, using a vibrating platform and taking calcium to build strong

bones, kayaking, gardening, lifting weights while watching TV, please share your fitness plan!

Yes, I want to talk to Linda Ambard, who runs marathons, and Dusty Hardman, who runs endurance races of 50+ miles. But I also want to hear from those who are trying to recover from the ravages of long-term misdiagnosis, and those who frequently spiral into adrenal crisis and yet are determined to get fit in spite of it.

Please send your comments before December 1 (preferably TODAY!) to COAST@Columbus.rr.com, or mail them to the address on the last page of this newsletter.

Exercise your brain

A CryptoQuotation just for fun

We've substituted letters in this quote so that one letter stands for another. Punctuation and the length of words are clues to solving the puzzle. The answer is below, but don't cheat!

OG UPI VSM'Y ARSTM YP FP DPZRYJOMH ERAA

ARSTM YP RMKPU FPOMH OY QPPTAU

If you can't learn to do something well, learn to enjoy doing it poorly.
From Dusty Hardman's website, Training Because I Can! At <http://addisonssupport.blogspot.com>

**COAST
CENTRAL OHIO ADDISON'S SUPPORT
TEAM**

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*Next COAST Meeting:
1 p.m. Saturday, October 11, 2008*

Pass the Salt, Please!

Elizabeth's Hot Chicken Salad

Elizabeth Wathen has shared this dish at COAST meetings—to rave reviews! Elizabeth writes, “I think of this as a “ladies lunch” dish. I used to serve it to the card club with biscuits and salad many years ago—maybe 40 years ago.”

2 cups cooked chicken
1 can cream of chicken soup
3/4 cup diced celery
3 hard boiled eggs, chopped
2/3 cup mayonnaise
2 teaspoons onion, diced
1/2 cup slivered almonds
Juice from 1/2 lemon
Potato chips

Mix all except chips. Put crushed chips on top. Bake at 350 degrees, 20-40 minutes.

Elizabeth notes, “Now I use fat-free mayo and Healthy Request soup. You can use more celery—or more chicken—or put cheese on top, or bread crumbs, or cornflakes. Or use more chicken, or omit almonds, or fewer eggs. Any combination is okay. Use more mayo and no soup—whatever you have.”

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