Written Comments submitted by Lisa Nagy M. D. To NTP/NIEHS

I would like to as brief as possible to be as effective as I can. I will summarize my personal experience as a physician (trained at Cornell Medical College) with Emergency Medicine and Surgical background who became deathly ill in California from a mold exposure. I am now relatively well and have been traveling the country over the past year speaking to my experience, and how environmental medicine practice alone is able to treat and diagnose these patients. My hope is that through your research the obvious symptoms that millions of us develop can be substantiated. From there diagnoses and treatment can be facilitated once the veil of secrecy and denial has been lifted about whether these patients are in fact ill from mold in the first place.

When I speak to the public, the most important concept that I explain is that I became very ill from Environmental Illness induced by mold (other chemicals can cause it but mold is probably the biggest offender now) and it gives me a new understanding of the ubiquity of these conditions in their mild forms in a large proportion of society. We are all on a 1 to 10 continuum of being environmentally affected. I may have been a 10. But no one is a zero. We are all exposed to car exhaust on the way to work, the dog and cat at home, pollen in the air and chemicals in stores. It is how we react with headache, fatigue, irritability, dysautonomia, asthma, itching, flushing, anaphalaxis that labels us as more or less reactive or sensitive. Many people have symptoms that are covered up or masked and they do not realize they are sensitive while in a toxic environment until they get away for about a week - then they blossom and become sensitivie to mold, their home, and chemicals. This is one of the discoveries made over 60 years ago by Rinkle in his study of his own allergy to eggs. He was raised on eggs every day. When he finally stopped eating them for 5 days as an adult he developed intolerable responses (syncope) to them when reintroduced. Thus was born the field of environmental medicine I suppose.

Now, I would like to say that your panel of experts should include at a minimum 5 members of AAEM (The American Academy of Environmental Medicine) many of whose members are versed in this clinical field. I would suggest off hand: Bill Rea M.D (Environmental Health Center of Dallas), Jean Monroe M. D. (Hertfordshire, England), Kalpana Patel (Buffalo New York). In addition Michael Gray M.D. has studied many patients as have Kaye Kilburn Phd. and Aristo Vojdani. They are not practicing environmental medicine and should utilized for Biomarker assessment and Neurologic testing guidance – be the subjects rats or human. My feeling is that there is no point in avoiding the people that admit the neurotoxicity and development of chemical sensitivity and immune and autonomic dysregulation in your quest for truth. Rather you should employ them and let other researchers learn from them what they have found out over the past 30 years of work in this field. From the following case, ideas for parameters to follow should be gleaned.

Intriguing Case Presentation:

In summary, I lived in Palos Verdes and had a huge Aquarium built into the living room wall (5,000 gallons of water). Around the aquarium the previous owner, a gynecologist, had built an untreated wood shed. He naively covered up one air intake for the house with this 'fish shed'. It never looked moldy – but it was in the wood probably everywhere. We never smelled it. But it entered the home 24 hours a day for many years.

The previous owner left and almost died of a mysterious pneumonia, later lost his license to practice medicine for erratic behavior. We moved in (1996) and over the next couple years I become dysfunctional and too weak to lift the laryngoscope to intubate at the Emergency Room! I quit my job (2000) and by staying at home where the mycotoxins filled the carpet, air and clothing I progressed quickly. I thought I was just depressed. I became too weak to wash my hair or brush my teeth. I couldn't turn a can opener more than once or fold a towel! My husband and I became confused and couldn't pay the bills. His face became reddened and he later developed Pemphigus (not uncommon in mold patients). I became allergic to touching the mail and reading the newspaper. My clothing tags drove me crazy in my clothes. My vision blurry, night driving was all halos.

I developed Addison's disease (2002) and lost 30 pounds and developed hyperpigmentation. My insulin tolerance test had a only small bump in cortisol (6) when the glucose was brought to below 20! What is fascinating is that two years later both my dog and husband developed Adrenal Insufficiency as well (by ACTH Stimulation test). All of us (2 dogs and 2 people) developed thyroid insufficiency. This may be pituitary in origin I do not know for sure.

After hormone replacement I still had muscle weakness and they thought I had Myasthenia and then Lou Gehrig's. I could not hold a smile, my diaphragm had 60 % of normal function. I used Mestinon to ventilate all night. I had a muscle biopsy and mitochondrial work up which revealed severe anoxic damage to the mitochondria by electron microscopy, targets and cores and atrophy. Clinically this was reflected in blue arms and legs and intolerance to rolling up sleeves or wearing a bra due to the ischemic injury. I had high lactate to pyruvate ratios illustrating the mitochondrial damage. My venous Blood gas was 75 when normal is 25. I was shunting tremendously at the tissue level. Trichothecenes also can lead to mitochondrial damage specifically (Wanamaker).

I got weak in stores and needed to lie down or use a wheelchair (at age 40). It turns out that I had severe dysautonmia (POTS) by tilt table testing. Because I had unknowingly developed Chemical Sensitivity, I was made more dysautonmic in stores where the air quality was worse (formaldehyde, pesticides at Home Depot etc.). I had neuropsych testing and had dropped my IQ from 160 to 100 and was in the bottom 10% of most tests. I looked wacky and anxious if not nuts (most do from the encephalopathy)

I eventually went to a meeting in D.C. on Chemical Sensitivity and heard a very sophisticated and understated Bill Rea speak on the subject. I knew I was dying and basically followed him to Dallas.

I was treated for a period of two months (IV Vitamins & Aminosyn, sauna, oxygen for 2 hours a day, Provocation & Neutralization allergy shots) and left with dramatic improvement and a long way to go. My Spect Scan showed severe

neurotoxicity and is somewhat improved now. I have now largely recovered – on almost no medication or hormone. I live on an island away from car exhaust, I jump my horse 4 feet a few times a week without difficulty, and I hope to return to work this year after I raise awareness about Environmental Illness and Medicine nationally. I give Grand Rounds and am forcing myself to speak on the subject weekly. Teresa Heinz, Kitty Dukakis, Hillary Clinton, are fully aware of me and my intent. Any help you can lend would be appreciated.

5% of the population has been found to be disabled by CS, 15% are sensitive to chemicals, and 40% are estimated to be affected unknowingly on polling. My feeling is that if it affects 74 million people to a mild extent at least then others deserve the treatment that I received who would never know how to find it. If an Ivy League trained doctor had no idea about Trichothecene Mycotoxicosis, Chemical Sensitivity, Chemical or hypoxia induced mitochondrial myopathy, endocrine failure as well as autonomic demise – then how is the average lay person to figure it out. Most mold patients have the same findings as I.

I am a walking testimate to the utility of the practice of environmental medicine. The first step is removing the inciting agent. I feel that ELISA testing of blood (Strauss) and urine for Trichothecenes and other mycotoxins is vital to making this diagnosis. Envirologix sells the Elisa Kit. Antibody testing was available until AristoVojdani's lab (Immunosciences) was brought down and he should be consulted in the development of all immune autoantibody tests. He has a genuinely good heart and has also recovered from this many years ago and like Bill Rea has unquestionable integrity. Dr. Vojdani has worked with the government before on Gulf War victims and would be honored to be consulted –I am sure.

As it stands now Trichothecenes are able to measured in dust vacuumed from clothing hanging in a contaminated house very accurately. I have done many tests of Trichothences and even found them high even in ordinary cardboard (.5 ppb). Of note I also found them high in horses urine (2 ppb and up) and have discovered an interesting fact that I will mention though I am no researcher. The horse eat hay and grain. Their sweat and urine have mycotoxins in them. When women who ride wash the sweaty pads at home they contaminate the laundry (especially the dryer drum which cannot be cleaned) and basically increase the exposure of the entire family. I unofficially proved this in a pilot of 25 people. Even children and husbands had higher values if the wives washed pads at home for 10 years as opposed to not!

I presented my interesting discovery and entitled the talk "Why Horse Women are Crazy". Any interest in a joint study would be great! I appreciate your time and am always available to discuss people, tests and ideas. I do not wish to disrespect the committee by the last discussion but want to let someone know the extent to which Trichothecenes are present in society unknowingly and what interesting things I have stumbled upon since my recovery.

In closing, I assume you are well aware of the GAO investigation this year by the Senate Health Committee (Chaired by Senator Kennedy) on the health effects of indoor mold. I am happy things are moving forward as I had discussed these issues with both Gwen Coleman at NIEHS and David Schwartz as well. In the coming year I would like to see and IOM meeting on Environmental Illness in general and will work to that end.

Sincerely and respectfully, Lisa Nagy M. D.

Included is a trifold flyer I made which has advice on taking an environmental history, treatments used in Environmental Medicine listed, and typical signs and symptoms for your records. I am always available to speak on this subject if you would like a lecture for your staff please tell me.

Member of the Committee for Advocacy – The American Academy of Environmental Medicine, Medical Advisor for The Healthy House Institute <u>lisa@nagy1.com</u> 508 696 6998 Assisting patients with health and mold issues from 10 AM to 10 PM all days.



LISA LAVINE NAGY M.D.

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PRESS RELEASE - FOR IMMEDIATE RELEASE Contact: Lisa Nagy, MD, 508-693-3048, <u>lisa@nagy1.com</u>

PHYSICIAN SHARES PERSONAL SAGA OF ENVIRONMENTAL ILLNESS AT 8TH INTERNATIONAL CONFERENCE ON CHRONIC FATIGUE

Ft. Lauderdale, FL January 7, 2007 – Lisa Nagy, MD, an ER physician who has recently recovered from severe Environmental Illness (EI) has been awarded the Sand Castles Scholarship to attend the 8th International IACFS Conference on Chronic Fatigue Syndrome, Fibromyalgia and other Related Illnesses, which will be held on January 10-14, 2007 at the Bahia Mar Beach Resort in Ft. Lauderdale. The International Association for Chronic Fatigue Syndrome(IACFS) has organized an comprehensive conference that includes programming for both patients and physicians, and Dr. Nagy will speak to patients on the subject "The Central Role of Environmental Treatment in Chronic Fatigue Syndrome and fibromyalgia as well as other neurological and immunological problems are all variants of 'Environmental Illnesses'. They can include viral, rickettsial, and fungal as well as chemical etiologies. Every person is different. There is not one unifying cause. Her own illness, until properly diagnosed and treated, mimicked Lou Gehrig's disease (ALS).

Dr. Nagy is shocked that doctors are not taught about EI in medical school and has committed her time now to bringing awareness of this condition to the public, medical community and governmental agencies. She says, "I will return to practicing medicine when 'Environmental Medicine' is a household name. In addition to speaking at conferences, she serves as Public Relations Chairman for AAEM, the American Academy of Environmental Medicine, helps others with environmental health problems from her home in Martha's Vineyard, MA., and offers a website, <u>www.environmentalMedicineinfo.com</u> for doctors and patients, which includes guidelines on "How to Take an Environmental History".

She works with AAEM because she thinks it is critical that people find a qualified physician who has been trained and credentialed in recognizing and treating EI. There are a wide range of symptom patterns that patients with EI can present with: Gulf War Syndrome, Chronic Fatigue, Fibromyalgia, Chemical Sensitivity, "Katrina' and '911 worker' related illnesses from mold, toxic dust and petroleum product exposures in air, food and water. The most common presentation, however, is among 'normal' women in their 40's who have seen a decline in their protective hormones and an increase in their sensitivities. Suddenly becoming allergic to the cat, or developing Attention Deficit, or becoming depressed can be a result of declining neurotransmitters, hormones, vitamins, fatty acids, and immune function in the face of an ever increasing environmental load. When the load is too great the person's health starts to decline in a way specific to that person's genetic susceptibilities.

According to Dr. Nagy, there are millions of women and children in the country who have allergies, ADD, anxiety, autoimmunity, and autonomic nervous system instability from environmental exposure to something as common as a moldy basement, new carpeting, or new kitchen cabinets which are high in formaldehyde. Dr. Nagy points out that anyone who has developed a dislike for perfume, diesel exhaust, the detergent aisle of the grocery store and whose cell phone heats up in their hands may be exhibiting early signs of EI and she feels strongly "We must get these people referred to the appropriate AAEM physician. The lay public should have the same opportunity to get well that I have had".

Contact AAEM for physician referral at their website <u>www.aaem.com</u> or at their office in Wichita, Kansas (316-684-5500) and Dr. Nagy at <u>lisa@nagy1.com</u>.

Where can the Patient Start to Get well? Easy Recommendations.

Start doing one thing at a time so as not to become overwhelmed.

Getting out of scented environment so you can tell what is affecting you. Therefore this is where you should start. Do not give up before trying! Read first chapter (very easy) of <u>Living With EI.</u> No perfume.

No 'normal detergent or Fabric Softener' (very Toxic for ill patients. Seventh Generation unscented, or Trader Joes only. Add Borax, or Superclean.

If you suspect mold then do cheap mold plates to get species identified and see how toxic.

If mold, vacuum dust, send for Trichothecenes. Absolutely get near no pesticides! No Golf, fly spray.

Non toxic shampoo (Pure Essential at Whole Foods). Buy nontoxic hair and body products from Needs (N) – unscented.

Make OASIS bedroom with charcoal air filter (N) Aireox quieter less EMF for small bedroom only, Austin Air Junior Plus, stronger for larger room,(both 300), hard floor, only cotton bedding (everyone becomes allergic to down), get cotton pillows (N), close windows if polluted or smoky outside.

Switch to non toxic: SG kitchen sprays, soaps,

dishwashing powder –(no orange scents), make up. Use recirculate button on car to avoid diesel exhaust.

Get masks if becoming more sensitive to go into stores or stay out of public buildings where VOC's make you ill.

*Order Mountain Valley Glass bottled Water. 800 643 1501.

Eat organic and start to not repeat foods except in 4 days. Less sugar, chocolate, wheat, dairy, carbs, coffee, soda. Drink lots of new water, plenty of salt of low adrenal function. Green Tea. If very sick eat one food per meal – easier on immune system.

Get salivary cortisol testing going, see environmental doctor.

Shopping – Whole Foods, Wild Oats,

NEEDS.com-Everything, hair dye 'herbatint', make up, Super Clean for laundry and floors, soap and detergent, I can Breathe 'mask', cellophane bags for

food, *Trisalts by Biotech, oral charcoal, NAC, Vits Less EMF.com, air tubing Headset, gauss meters, apron

Safelevel.com, out gassed computers with EMF shielding

EHCD - 214 361 9515, charcoal masks, O2 set up, books

What is Environmental Treatment?

First and most important is clean Air (filtered), Food (organic), and Water (glass bottled).

Identify the initial causative agent(s) that made you sick. Often moldy basement, office, golf course with pesticides, ,paint fumes, 'Gulf War', 911 workers

Avoidance of that which is making you sick and most other chemicals until you can again tolerate them and stay well (in a few years). Leave moldy house.

Oral (Fish Oil, Co Q 10 400 mg) and IV supplements like Vitamin C, B complex, Magnesium, Glutathione, Taurine, Amino Acids, phosphotidyl choline, glass bottles – to assist in breaking down toxins efficiently, strengthen the adrenal and immune system. Discover all metabolic and nutritional deficiencies. 4 Day Rotational Diet.

Neutralization and Provocation Allergy Testing (150.00/day) to grasses, trees, molds, foods, viruses, supplements, and chemicals, even your own stool and blood ('Autovac').

Treating with Oxygen if the Venous O2 so indicates (greater than 30) for 2 ½ weeks or longer, 2 hours a day, 5 liters, with 'set up' from Dallas (ceramic mask, tygon tubing, humidification bottle, and rebreathing frame. Dramatically helps ANS!

Sauna, massage, other detox methods - coffee enemas. Do not start sauna without EM guidance you may 'CRASH' when you release all the stored toxins from your fat. Goal 20 min of sweating /day.

Determine Genetic inadequacies and treat to counter act deficiencies in detoxification or immunity.

'ALF', Autogenous Lymphocute factor, which assists in boosting the immune system and is AMAZING (only available in Dallas, personally recommended for anyone at an impass). (Keeps me alive.)

Hormone studies and replacement of all that are low, Thyroid replaced clinically even if numbers are 'normal'(as long as cortisol is good first). If indicated, *cortisol early to motivate patient*, 5mg qid

Study urinary neurotransmitters and replace deficiencies with amino acids and wean off psychiatric drugs as hormones and neurotransmitters 'normalize'.

Chelation of heavy metals oral or IV, with mineral replacement. Remove 'high voltage' dental work early in Rx. and amalgams at IAOMT dentist. Test new composite/porcelain for allegenicty. Energy treatments, Cranio Sacral, massage, acupuncture

All that works and doesn't harm the patient. 'Midodrine for POTS'. *Take Trisalts, 2,000 buffered C, and Oxygen,Epsom Salts bath when ill.

HOW TO TAKE AN ENVIRONMENTAL HISTORY

Doctor and patient guide to identifying EI

Environmental Illnesses include:

Common syndromes which can culminate in Chronic Fatigue, Fibromyalgia, Chemical Sensitivity, Chronic Lyme as well as other milder conditions like allergies, anxiety and ADD.

They have **environmental**, **nutritional**, **hormonal**, **and genetic** components that need to be practically addressed.

When you: find **perfume, diesel exhaust**, and the **detergent isle** of the grocery store offensive – have **memory loss**, fatigue or weak **muscles**, trouble **reading**, clothing tags itch, need to pretzel your legs, a reddened face, or alcohol intolerance

- *it is time to see the* Environmental Physician at www.AAEMonline.org

'This is the most important medical issue facing women in America today' *Lisa Nagy M.D.* Work Up, Lab Tests, Home Water

Brief Screening History-- Questions to Ask Your Patient

When did you last feel well?

What changes in your life occurred before that time? *Known chemical, mold, radiation, pesticide exposure. ? What do you think has precipitated your condition?

Examples: Did you renovate your home, get new kitchen cabinets, carpeting, spray pesticides? Have you changed jobs or had less ventilation at work or a new copier or computer installed. Are others sick – even if the symptoms are different?

Are you sensitive to perfume, diesel exhaust or the detergent isle of the grocery store. Do other chemicals, newspapers, the mail bother you? Sleepy, headaches?

- Do you feel better outside in fresh air? Do you fall asleep or get a headache in traffic, feel exhausted in stores, tire centers, or moldy buildings? Are you better on the weekends and worse on return to work. Do you have a moldy basement or does the house smell musty when you first come home?
- Have you been avoiding dealing with a water leak? Do you have a crawlspace? Are you worse in the Winter when inside more and the windows are closed? Feel bad on rainy days.

Do you pretzel your legs after eating? Dizzy on standing from bending over recently? Insomnia.

What part of the year gives you the most trouble? Do you have symptoms in many different areas?

Do people think you are a hypochondriac. Does your husband think your are wacky?

Have you not been helped by many other physicians? Can you tell you have a physiologic not a mental problem? Do others think you have mental difficulties and that you tolerate stress very poorly? Do you have short term memory loss? Do feel you are definitely ill but no one can figure out why? Are you intolerant of electrical appliances, fluorescent lights. Does the cell phone heat up in your hand or give you a headache. Do you use Tide, Downey or Bounce? Lawn treatments?

Physical – some classic signs

'Allergic shiners'. Nasal Polyps, Poor Rhomberg (standing on toes with eyes closed - have a spotter) and walk heal to toe eyes open then closed. Rosacea or flushed face, nasal turbinate inflammation, rashes/lesions (mold), cannot do squats (suggests mitochondrial damage), dry unkempt hair (mold, hypothyroid), distractible, loquacious, irritating, aggressive. Check for fillings, crowns, infections, 'adrenal teeth' (crowded). Fungal infections of skin, Nails, vagina, groin and dandruff. Adrenal pupils.Facial hyperpigmentation. Loss of lateral third eyebrow (thyroid). Poor cap refill, bluish limbs, anxious on sitting near air filter, fluorescent lights or fridge.

Look for breast or other implants. Petichiae. Bruises. Neuro: short term memory very poor, color discrimination, concrete, thinking may be floridly psychotic or neurotic which will clear with treatment eventually – multiple causes. Do not discount signs and symptoms because of patient's psychiatric presentation. Treat the whole patient – ignore the mental instability for now. Reassure that this is treatable and they will get better.

Common Patient Complaints Characteristic Of EI.—If they are still

'masked' they might be wearing too much perfume and fabric softener, and <u>unaware that they are</u> <u>developing sensitivity at all yet.</u> Patients may have many or few of these: Waking up with sore throat from too many VOC's in bedroom. Morning headaches (mold in bedroom). Feels better when sleeps with the window open, Asthma, shortness of breath in stores

Clothing tags are extremely irritating to the skin and must be cut out. Increased sensitivity to smells chemicals, sounds, spaciness, cannot read. Muscle weakness (cannot wash hair), neurologic problems, difficulty standing with legs apart and talking without leaning or crossing legs (mild dysautonomia is in 85% of patients). Feel like lying down in stores (VOC induced dysautonomia). Difficulty reading and remembering what is read.*Blurry vision while driving at night. 'Second wind' late at night? Hypo-manic, OCD, ADD, Depression (mold), extreme tearfulness (low cortisol), anxiety (low DHEA), lower I.Q. Hormone (adrenal, thyroid, testosterone, HGH) deficiency syndromes.

Bras are too tight, Bp cuff hurts to blow up, rolling up shirt sleeves is painful (tissue ischemia). Allergies increasing to cats, down, latex gloves, newspapers and mail – red itchy hands and headaches. Early hangovers (poor methanol metabolism), intolerance to alcohol. Alcoholism (low cortisol). Belligerence (men) from low growth hormone and testosterone. Heat intolerance, post exertional exhaustion. Too cold in the grocery store, arrythmias, seizures, asthma, irritable bowel.... Inability to get up in the morning, motion sickness, new fear of heights, bridges. Cannot tolerate airplanes, Jet fuel, magazines on plane. Fall asleep at wheel due to diesel.

And Mold Tests

*Venous Oxygen -VBG, A great screening tool. At hospital, no tourniquet, anticubital vein. Call and arrange with lab Normal is 20-25. Treat with O2 if > 30. >50 severely ill, read Von Ardenne on therapy. Doctors Data 800 323 2784, heavy metals etc. Immunosciences - immune panels, viral Ab, SOD and GSH Acuchem Labs 800 451 0116, Pesticides, Aliphatics, PCB's Metametrix 800 221 4640, 'Cardio ION Profile' 800.00 Salivary Cortisols- a must at Diagnostechs (800 878 3787) 99.00 -also at Labrix, & Genova Diagnostics who also does Detoxification and Immune Genetics (400.00), and more. 'Iodine Loading test' 877 900 5556, 75.00 *** Only in Dallas: T and B cell counts to be 'ALF' candidate. Serum hormones Testosterone, SHBG, IGF-1, dhea-S, aldosterone, cortisol and CBG, pregnenolone, Reverse T3 total and free T3, FT4, and TSH, Est, Prog, Urinary hormones, serum thyroid profile with reverse T3, Meridian Valley lab (425 271 8689). 300. Urinary Neurotransmitters, Neuroscience 888 342 7272, 200. WATER National Testing labs 877 900 5556, <150.00 test tap water for pesticides, chemicals, and metals. MOLD P & K Microbiology - 866 871 1984 for malt agar mold plates 70.00 per room with speciation. 4 colonies/1 hour OK. Pure Air Controls 800 422 7873, order 'dust socks' and Vacuum dust from clothes or carpeting for Trichothecene. Dr. Hooper 214 764 1165 urine mycotoxins, 350.00 and PCR. Antibody Testing:Various Labs. **REFERENCES:** *Living With Environmental Illness, Stephen Edelson must read first chapter to get understanding of the field. Less Toxic Alternatives, Carolyn Gorman will use forever! Tired or Toxic, and newsletter Total Wellness, 54.00 By Sherry Rogers 800 846 6687. Doris Rapp, books on kids too, great videos on Oprah. *'Environmentally Sick Schools' 800 7878780 Videos by Alison Johnson. *MCS and Gulf War, 'Toxic cloud of 911', 207 725 8570. HEAL newsletter, 404 248 1898

Chemical Sensitivity 4 Volumes by William Rea M.D.