

## ECD Global Alliance

Cases Represented in the Group (Last Updated March 2009 – Plans Underway to Update in Second Half of 2010)

Case #	Sex	YOB	Dx date	Age at Sx onset	Age at ECD dx	Symptoms (Sx)	ECD Involvement	Treatments Tried	Current Treatment	Current Status	Last Update Date
1	M	1972	11/07	21	36	Lightheadness, Kidney issues in 1990's dx'd as multi cystic dysplastic kidney disease, controlled by meds. Chronic sinus problems. MRI showed masses behind the eyes. Surgery revealed a benign scar tissue type mass.	Lesions on the brain, mass behind eye, kidney, long bones of leg.	See Current	Tamoxifen. Doctors are suggesting cytoxan because of past success with this drug. Patient hesitant to switch due to desire to have children.	Tired from tomoxifen. Night sweats sometimes.	4/10/2008
2	M	1940	7/07 at death	45	66	1980's first symptoms were high blood pressure dx'd as renal artery stenosis, profuse perspiration, and itching/burning sensation after a shower. In 1999 had pain in knees, shins, lower back and flank dx'd as age related. In 2001 had night sweats, muscle cramps, anemia dx'd as myelofibrosis. In 2004 had extreme weight loss, extreme fatigue, nausea, numb upper lip, back rash, small, longstanding skin lesion bx'd, congestive heart failure, brain lesions, kidney failure, dialysis, fevers of unknown origin, kidney transplant. After transplant (2005 – 2007) had balance issues, slurred speech, loss of tooth material, extreme and urgent need to urinate, extreme pain in various parts of body, shortness of breath, double vision, excessive mucous in throat, swallowing issues, many infections. Surgery to remove mass on adrenal gland was aborted due to benign scar-like tissue around the vena cava. Adrenal gland biopsied 2 separate times. In 2006 required stent in ureter of transplanted kidney due to stricture thought to be result of chronic UTI infections. Complete workups at Methodist in Houston, M.D. Anderson and Duke with no diagnosis.	Kidney, brain, adrenal gland, heart, lungs, perito-neal area, teeth, virtually entire body.	Kidney transplant in 2004, anti-rejection drugs (prograf, cellcept, prednisone) from 2004 until 2007; inpatient methyloprediso nole 1g/day x 5 day steroid treatment in 2005, IVIG treatment in 2007	n/a	Deceased 7/2007	7/12/2008

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3	M	1970	2006	25	36	Bone pain in right femur, diabetes insipidus. Diagnosed with LCH in 1995 after lesion removed from right femur. Inability to have children due to drugs. Lesion removed from skull in 2000. Kidney involvement in 2005. New biopsy of left pelvic bone led to ECD diagnosis.	Head (pituitary gland), eyes, kidney, bones	Surgery to remove lesion in right femur (1995). Titanium rod placed in femur at that time to support the bone. (DDAVP for Diabetes Insipidus)? Surgery to remove tumor on skull (2000). Steroid injections and radiation to remove tumors behind the eyes (2001, 2002). Radiation for pituitary growth (unsuccessful). Interferon (stopped in 11/06 after 8.5 mos. as he did not respond well to it and had severe side effects if he took other medication), chemotherapy (Vinblastine & prednisone - 3 treatments) helped shrink a bone tumor, but side effects were bad. Tried Methotrexate and Remicad in 2008 but quit treatment due to side effects.	Pain medication, Interferon 1 mu/ 3 x week	Bone pain, balance, speech problems (affected by weather). Recent high blood pressure. Had night sweats for about a year, but none recently.	02/12/2009

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4	M	1956	4/06	46	50	Earliest symptoms, night sweats, fever, WBC High, RBC Low, overall cholesterol levels low, LDH high; C-reactive protein level from lowest of 57 to high exceeding 100. Thigh bone, knee, ankle pain, tired easily, w/ general feeling of malaise. Just prior to dx 4 yrs from onset of symptoms, had lost 25 pounds, was in Congestive Heart Failure, Fluid both lungs, weak, very anemic, in constant pain, fever, legs, ankles swelling. Had, MRI showed excessive lymph nodes, which led to abdominal surgery to take biopsies f/u with CT and CT Pet. Platelet issues required transfusions prior to surgery, steroids. Continues w/ Leg pain, entire skeleton, back pain and High blood pressure. Osteoporosis, lower spine. Recently developed itchy spots.	Kidney, abdominal aorta, bone in lower back, neck and legs, mandible.	Current only.	Interferon 5 MUI 3x week since diagnosis, plan is to remain on this long term; prednisone 5mg; Toprol XL & Altace for Blood Pressure; Prozac to negate side effects of Interferon (can be rage, suicidal)	Doing well, disease slowed down on interferon. CT PET shows no more affected sites. Previous sites show no activity. Very tired from interferon, especially the day following the shot. Zero energy, takes lots of naps.	6/09/2008

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5	M	1962	10/06	40	44	<p>Poor balance and some slurring of speech and itchy spots. Had one major epileptic fit and some partial seizures so not allowed to drive. Epileptic seizure provoked more investigations. Previously had double vision, slurred speech and wobbliness. Brain MRI &amp; removed longstanding skin lesion indicated EDC. Some night sweats. Lost weight while hospitalized in 2007. Odd sensations in the front part of the soles of feet (like numbness after having a jab although they aren't numb when they are touched). Problems with bladder needing to pass urine often and in a hurry (not believed to be diabetes insipidus).</p> <p>A PET scan after the last cladribine treatment had finished in Jan. 2009, showed a reduction in the activity of the disease. The PET will be repeated in 3 months. Going to Paris in early March to see Dr Haroche for assessment and for any advice he can offer, and to be part of his research project.</p>	Brain, chest, skin, eyes and retroperitoneal area.	Has been on (1) Interferon, then (2) azathioprine and then (3) cyclophosphamide and then back to (4) only interferon 3mu every other day and then (5) subcutaneous cladribine subcutaneously for 5 days consecutively at intervals of one month, for a total of 6 months beginning in July 2008 due to activity seen in bones for ECD.	Lamotrigine for epilepsy, Warfarin due to pulmonary embolus, tolteridine for bladder problems and fluoxetine for depression and ,finally, co-valsartan for blood pressure. No specific treatment currently for ECD.	Retired at 46. Generally improved. Less slurry; only use sticks when I go out, stair lift only occasionally (after too much slurp); only one pair of glasses needed for reading and distance; swallowing usually OK so the weight is piling on!; still coughing quite a lot. Restarted regular trumpet lessons, and doing voluntary sessions in local neurology ward and a local "resource centre for those with chronic neurological conditions". Also making bread, cakes, and jam at home.	2/13/2009

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6	M	1964	6/07	43	43	2 months of sudden and intense illness. Initially thought food poisoning or stomach flu. Remained nauseated, began losing weight, gray colored stools. Three weeks later developed 104 degree fever. Extremely jaundiced. Then thought he had hepatitis. Entered into hospital via ER for 1 month hospital stay with liver, kidney, lung and heart failure. Lung biopsy resulted in major bleeding issues due to low platelets. Night sweats, but they were while on steroids.	Liver, kidney, lung, heart.	Steroids, interferon.	Interferon 6 MIU 3x week. Prednisone 4 mg (tapering off). Plan to taper interferon to 3 MIU when off prednisone. Bone marrow stem cell transplant on hold because ECD is stable and risk of transplant.	Feels worn out from interferon, feels like he had the flu, but not too bad. Stable. On blood pressure medicine. Anemic. Has numbness in right leg, strange sensations on foot.	4/10/2008
7	M	1962	6/07	40	45	Growth in head. Diabetes insipidus. Pituitary 'halo' found via MRI in 2001. Had to let head growth grow to allow for a biopsy. Biopsy from behind eye in 6/2007. Biopsy id'd as Xanthogranuloma. Full body bone scan ("lights up like a Christmas tree")	Head, peritoneal aorta, kidney, legs from the femurs down	See Current	Interferon 3 mill. units 3xweek since 8/07 (dosage reduced in 6/08). Fentanyl patch for pain.	Stable, no new growths. Feels ok, but very tired..	6/15/2008
8	M	1963	5/05	34	41	1997 noticed initial dizziness when climbing up high. Developed loud snoring in 2003 but not sleep apnea. Testing at that time showed high blood pressure. 2004: worsening balance & dizziness, slurred speech and emotional incontinence. CAT scan showed growth in kidney and puffiness around kidneys. Bone scan indicated ECD. Biopsy of kidney growth confirmed ECD. Currently chronic constipation, sexual problems. Diabetes insipidus since childhood due to injury to head. Stamina and strength have decreased, but mostly that is from the lack of physical activity. Balance and speech issues continue, but have adapted to them. (12/08 – speech and cognitive issues seem to be getting worse, but no pain issues)	Cerebellum -pons- pituitary area of brain, kidney 'halo' and lesion, femurs	2CDA in 2005; stable since then.	Avapro & Norvasc for high blood pressure. Nortriptylene for emotional incontinence. DDAVP for diabetes incipidus. CPAP for sleep problems.	Stable since 2005. Some good days, some bad. Mayo clinic in April, 2008, showed no changes in scan for last 2 years.	7/9/2008

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9	M	1967?	10/03			Swollen eyes, achy joints, slurred speech, wobbly walk.	Lungs, eyes, nodes under jaw.	Remicaid and Methotrexate along with Cellcept	None since 11/06.	In remission since 3/08.	4/16/2008 (incomplete history)
10	F	1967	2007	37	39	Night sweats and leg pain. Tired and cold with intermittent fevers. Internal pressure inside head and optic nerves, treated with LPI to release pressure immediately and meds of Umerux and Prednisone .After 6 months of treatment pressure disappeared. Diabetes insipidus 3 years after onset of symptoms. From 2006 - 2008 ears plugged with yellowish discharge that must be removed once a month.	Kidney, bone, brain.	Initial treatment was Vinblastine 1 x week, Aredia once every 3 weeks both for 7 months. Naxin (pain med) 2 x day, Calcium w/D for 3 months. Symptoms were improved. Prednisone for 8 months beginning at 100 mg/day stepping done to 0 mg.; Interferon as high as 9 mil x 5/week in 2008 to stabilize the disease. Had LPI 3/08 to decrease head internal pressure.	Interferon (9 mil) 2 x week; Vinblastine once every 3 weeks; Aredia 1 x month, Naxin 1 x day. Infusion of pamidronate every 30 days. Shiatzu and acupuncture.	Stable, but not feeling well.	3/3/2009

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11	M	1952	1998	44	46	Increased thirst (Nov 1995) 4 plus gallons of water per day. Low blood pressure, swelling (legs, face), Low grade fever (for 3-1/2 years) (1996). Shin pain (1997). Bone pain (1998). Slight reduction of tissue (abdominal, kidneys) after off of morphine. Last 7 years I've remained stable (no increased tissue). Learning to deal with fatigue through better nutrition. Control pain with brain wave stimulation.	Skeletal, Central diabetes insipidus, osteoporosis	Three rounds of chemo, vinblastin, 2cda, didn't help. 2 radio active injections of Samerium 265 (or 285) didn't help. On morphine for 33 months. highest level 400mg per day, off in 11/2001 with the help of brain wave stimulation.	Pamidronate every 60 days to prevent bone break down.	Osteoprosis in my lower back.	7/13/2008
12	M	1940	06/04	54	64	Began with pain in the long bones of the legs in about 1989. In 1/04 stomach began getting bigger and would feel full after eating only a few bites. In 12/03 began having chills and fever every evening. In 12\01prior to knee surgery an MRI revealed what was thought to be prostate cancer. (Prostate had been removed in 1990. Prostate cancer was retreated in 1998 with radiation therapy and PSA was normal one month prior MRI of knee so return of prostate cancer was not considered a correct diagnosis.) Knee surgery in 01/2002 resulted in infection of the knee. In 04/02 began having problems with legs again and orthopedic surgeon wanted to do a biopsy of Rt. leg above and below knee. This resulted in having a bone biopsy of hip which resulted in an infection. In 03/04 fatigue and shortness of breath resulted in a consultation with an infections disease doctor who ordered a CT of the pelvis, abdomen and chest. Within two days 2200 cc of fluid was removed from the sac surrounding the heart. 8 biopsies of stomach tumors were done with no definitive diagnosis except none malignant. A month later finally got a diagnosis.06/04	Masses in stomach, chest, and Behind eyes, involvement in bones skull, shoulders, arms ,Legs, & hips	Round 1- 24/7 of 2cda chemo , 7/04 Round 2 was 1 treatment each for 4 days, 9/04 Round 3 was 1 treatment a week for 6 weeks.	Prednisone 10 MG per Day	No new Masses since 09/02  lots of leg pain, Eyes, ,Leg Weakness  Lower back or left hip has pain along with legs.  But patient is glad to be up and around	2/15/2009

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13	F	1955	24 <sup>th</sup> Dec., 2005	41	48	<p>1995: (possible sx's): large fibroids in uterus necessitating hysterectomy 1995, no dx of fibrosis at the time remembered: 1999: (probably ECD related?): severe 'heartburn' pains: dx'd as narrowing of the coronary artery supplying blood to the right atrium - a stent was implanted 1999 – an unusual cholesterol/triglycerides ratio was noticed (very low HDL giving HDL/Triglycerides ratio that indicates very high likelihood of coronary artery disease – the material blocking the artery was said to be cholesterol but no biopsy was done.2001: Definite ECD symptom: fluttering / waviness in peripheral vision – biopsy taken: dx: Acute Idiopathic Orbital Inflammatory Syndrome – fibrotic tumour growth around both optic nerves. The biopsy material was retained and used in later analysis. Treatment with cortisone (75mg/d for three months reducing to 10mg/d over three months before coming off) slowed growth but did not reduce size of tumours. Radiation treatment on both eyes had no effect. Treatment with Imuran reduced the size of tumours somewhat relieving pressure on the eyes – by 2004 the growths stabilised and vision returned to a reasonable level however glasses are now needed permanently and cortisone led to the onset of Type 2 diabetes.2005: 'galloping in the ears' / very high blood pressure: scans showed a growth in the retroperitoneal area, adjacent to but not enclosing the aorta and invisible but probably enclosing and compressing both renal arteries (hence the high bp). Biopsy of retroperitoneal mass confirmed fibrotic tissue. A stent was inserted into the right renal artery, eliminating the blood pressure problem and treatment with Tamoxifen &amp; Imuran has stabilised the tumours (no growth, no shrinkage) has been seen in over two years.2006: Ophthalmologist did research work and initiated a review of all the available material including carrying out scans of the long bones: a firm dx of ECD was made, confirming the treatment regime as appropriate. Re-evaluation included both biopsies which were now interpreted as characteristic of ECD 2007: scan done which showed no change in the size of the tumours in 4 years even though the specialist in looking inside the eye had expected significant improvement: Lifelong (since 16) hypothyroidism. Lifelong difficulty with metabolising fat</p>	<p>Retro-ocular area surrounding both optic nerves; retroperitoneal area with two visible growths around renal arteries, probably fibrotic tissue related to that biopsied from the retroperitoneal area</p> <p>Density changes/lesions to all long bones (arms and legs).</p>	<p>For Eyes: Cortisone; Radiography; Imuran Retroperitoneal growths: Tamoxifen.</p>	<p>ECD meds are combination of Imuran (for eyes) and Tamoxifen (for retroperitoneal growths)</p> <p>Other drugs at present: Oxixone: for thyroid; Amaryl / Diaformin: for diabetes; Cartia / : for coronary artery disease; Lipitor: for cholesterol control; Atenolol &amp; Karvezide for blood pressure; Panadol if needed for pain relief (avoided when possible); Tea Green for removal of radicals/toxins; Fish Oil for arthritis</p>	<p>Condition remains stable (2009) but no indications the ECD growths are reducing.</p> <p>Lots of walking to maintain mobility</p> <p>Pilates &amp; Osteopathy to maintain flexibility</p> <p>Muscle spasms / strains / pain happens frequently and easily. Bone and muscle pain is present continuously but at variable levels of intensity. The use of a Homedics Percussion Massager (model PA-MH) reduces incidence of muscle cramps, especially those occurring during sleep</p>	<p>Most recent doctor's visit: Feb. 2009.</p> <p>Most recent update of this info: 2/2009</p>



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14	M	1964	1996	28	36	Initial problem was a small growth on pituitary gland discovered around 1992. Later when dizziness became an issue the growth on the pituitary gland was removed and as a result blindness occurred in right eye. Began taking testosterone injections and enjoyed a period of feeling good. In 1996 while in Michigan the symptoms returned and had another surgery to remove tissue from the brain stem and optic nerve. This resulted in balance issues, reduced sight in the left eye. The doctor did not understand what he was seeing and put the case on the computer. A doctor from Korea actually came up with the diagnosis. Previously had issues with colon disease, but now temporary colostomy has been removed.	Eyes, lung, kidney, brain	Chemo - vp16 topicide – 3 days of treatment in a row each month (did for 3 years, stopped for summer of 2008 due to side effects)	DDAVP (for diabetes insiidus); Hydrotcort; Synthroid; Prevacid; Lopressor; Lasix; Lovastatin; Humalog; Nutrophin; Testosterone injection; Lyrica; plnng to start interferon on Oct 13, 2008	No new tumors, old ones are dying;  worried about losing eyesight  balance issues, slurred speech, & tires easliy	9/20/2008

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15	F	1950	5/1/00	38-40	49	At least ten years of severe hip/leg/knee pain. Can't remember exact date of onset. Was diagnosed during this time with fibromyalgia, chronic fatigue syndrome, lymphoma, arthritis. Diabetes Insipidus onset in 1990. Hyperthyroidism onset in 1998 but may/may not be connected. Significant weight <i>gain</i> during last fifteen years. Routine abdominal CT in 2000 showed retroperitoneal mass with extensive arterial involvement. Remained steady with no new symptoms for three years, then mass had grown around ureters necessitating stents. Histiocytes constantly blocked them necessitating placement of new stents six times in nine months. Had a bilateral nephrostomy in 2003 and it continues to manage the situation, although kidneys are filling up with histiocytes and there is concern over how much longer nephrostomy will be viable. Constant problems with leaking at the port on one side of nephrostomy and constant urine scald/cellulitis on that side. Had one round of experimental chemo in 2000 but it had no effect on mass. Continue to have aching in lower spine, weight bearing bones and more several pain in feet, which tends to come in cycles. Control the pain with Tylenol w/codeine and, on days when I know I'll be on my feet a lot, I take Hydrocodone. Occasional low grade fevers that go away with one dose of Tylenol. Biggest problem is infection in/around leaking port. Tend to have about one day a week that is a "down" day - aching and malaise. Started having problems with one eye in December 2006 that was diagnosed as blephoritis. Problems continued through 2007, with heavy watering. Noticeable bulging in early 2008 and CT showed orbit was filled with mass. Vision is not impaired as of yet. Started Interferon Alpha, 3MIU 3x/wk, 3/31/08. CT after three months show no change, good or bad, in orbit. No problems with Interferon as long as I get plenty of sleep at night.&n bsp;	Masses in abdomen, kidneys, lower spine, hips, legs, knees, feet, orbit and pituitary	One round of chemo, otherwise just treating symptoms	Interferon Alpha 3MIU 3x/wk since 3/31/08, pain medicine as needed, Prednisone, 10mg, daily, BP medicine needed as a result of Prednisone	On disability as of 5/31/2003, able to continue with all normal activities except for walking distances. Self care for nephros-tomy which sometimes needs bandage changes as often as every two hours. CT shows no change 3 mos. after starting interferon treatment. Very low energy, hip/leg/foot pain and loss of flexibility in lower extremities.	7/12/2008
16	M	1950	1986			Bone loss in lower jaw. (waiting for rest of information from patient)					
17	M					(waiting on information from patient)					

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18	F	1932	Spring 2008	74	76	<p>First symptom was double vision. After repeated attempts to correct the problem with glasses it became obvious something might be really wrong.</p> <p>August 2008: Scans showed no change in eye, abdomen, or mass at base of skull. First skeletal survey so done and bone involvement was seen. The eye has had noticeable improvement in the protrusion, but is not documented by the radiologist as the initial scan in fall 07 and the more recent one in Feb08 were done at two different locations.</p>	<p>bilateral. xanthogranulomas in her eyes; a mass in her abdomen; a mass at the base of her skull in the spinal canal; showing areas on her proximal tibias</p>	<p>Dec 2007: Tried 1 month steroid burst which showed mild improvement but with severe side effects. June 2008: Began interferon at 6mil. Aug 2008: Interferon lowered to 3mil due to adverse side effects. Sept. 2008: Again reduced the interferon dosage down to 1 MIL 3Xweek due to side effects of exhaustion, malaise &amp; weight loss</p>	<p>Interferon 1MIL 3xweek</p>	<p>Concerned about eyesight.</p>	<p>9/25/2008</p>

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24	M	1945	Sept. 2007 suspected; confirmed Jan. 2008	62	62	<ul style="list-style-type: none"> <li>In January 2007, patient complained of right ankle ailment: slightly swelling at time; still remnants of "black and blue" from a softball injury sustained four to five years earlier when stepping on a base and catching on back edge with full weight. This led to a comprehensive battery of tests and exams (metabolics; chest and pelvic x-rays; Thoracic, abdominal and pelvic CT scans; and a venous extremity with doppler of the right leg. All results were normal - except the CT scan of the pelvic/abdominal region indicating two soft tissue masses surrounding both kidneys.</li> <li>Other than discovery of the two tissue masses, no other symptoms experienced. A succession of five medical specialists (hematology, oncology, radiology, urology, and nephrology) at two major hospitals and two biopsies resulted in a preliminary diagnosis of retroperitoneal fibrosis (RPF). Two biopsies (1st - local left renal; 2nd - laparoscopic left renal) were conducted in succession over two months; each proved inconclusive. A review of CT scans and xrays in pelvic/abdominal area reveals NO soft tissue around the aorta in this region (clinical cases define RPF as having such soft tissue in this region. A bone scan with Tl-99 led to a change in diagnosis to Erdheim-Chester disease in September 2007. Patient during this period was frequently asked by medical professionals how he felt. He always responded "Great! It's only you doctors who tell me something is amiss."</li> <li>Other than the two tissue masses surrounding the kidneys and the "long bone evidence" in both legs and arms, there is no other involvement of any other organs, to include the brain, eyes, lungs, etc. These organs are CT scanned periodically (every 9-12 months) monitoring any change. Metabolically, all organs were performing within their norms and these are checked monthly.</li> </ul> <p>If I could offer any encouragement to others, it would be these two adages: "Dream/Plan as if you will live forever; live as if you will die tomorrow." and "Forget the potholes in the road of life. Celebrate the journey."</p> <ul style="list-style-type: none"> <li>Be strong! Keep the faith!</li> </ul>	Kidney, bone	<p>Prednesone was utilized for the first four months in concert with CellCept. Starting month: 40 mg/day. Second month: 30 mg/day. Third month: 20 mg/day. Fourth and last month: 10 mg/day. CellCept was taken from the first day/first month at the dosage of 1000 mg, twice a day and continues.</p>	CellCept 1000 mg x 2 per day.	No visible symptoms. Fairly healthy and physically active throughout life; accomplished many goals and still has a few more to tackle	2/20/2009

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32	F	1938	2003	55	65	Liver enzymes elevated; red spots on skin; elevated sed.rate (100); chest x-ray showed unusual spots in lungs; sinus problems. Occasional joint pain, fatigue, anemia, CT scan showed unusual material in abdominal area, vision problems, thyroid deficiency. Lung biopsy at Mayo in 2003 showed ECD. Consulting doctor knew nothing about ECD.	Lung, eyes, abdominal, thyroid	None	None	Am concerned about anemia, lungs, eyes, plus whatever may be a problem in the future that is not currently affecting things	2/21/2009
34	M	1968	1/30/2009	39	41		bone, lymph nodes, kidney & heart		PEGASYS interferon alfa 2a 150 mcg injection once a week	Just started treated on 2/11/09 will see how treatment progresses	2/13/2009

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36	M	1953	Mar. 1999	43		<p>First sign was double vision, but the neurologist couldn't find the cause. In 1998 more problems with eyes. Vision was not stable and left eye was bulging. Diagnosis was given as Graves disorder. A CT-orbita showed tumors behind both eye-balls in the orbita. In January 1999 a biopsy was taken, a lipid deposit called xanthogranulomas was found. A lot of scans (thorax, abdominal, skeleton, hollow pipe-bones, MRI, SMS), biopsy of a kidney, bone biopsy, bone marrow biopsy and tests (blood, thirst) followed and in March 1999 a team of internal medicine doctors were convinced of ECD diagnosis with a beginning diabetes insipidus. The disease had spread out in my body: xanthogranulomas is behind my eye-balls, spots of lipid deposits are found in the bones (hollow pipebones above knees, in hipbones, shoulders, chest, skull, lungs, around the kidneys, around the aorta and cerebral membrane (along the tentorium).</p> <p>In an attempt to save the optic nerve, Cytostatica Solu-Medrol iv followed by another cytostatica called Endoxan iv were tried with no sustainable effect. June 1999 a decompression of the orbita was tried where bones in eyesockets and cavity of nose were removed to make more space in the orbita with no sustainable effect. 18 sessions of Radiotherapy with a temp. improvement in vision. Jan. 2000 a 'debulking' surgery (removing lipid deposits out of the orbita behind left eyeball) was successful and sight was regained in left eye.</p> <p>I have learned that it is important to believe in the good things of life, enjoy each day and make each day a good one with my wife and kids, my family and friends.</p> <p>I discovered my sources of energy and fun, and they brought new and unexpected dimensions, which surprised me so much.</p> <p>For example, I found my guitar again. Making songs and music give me power, satisfaction and a lot of fun.</p>	Eyes, bones, lungs, kidneys, heart, brain, chest, pituitary gland	<p>Drug cocktails over the past 10 years have included:</p> <p>prednison-cyclosporine-octreotide-minrin-renitec-fosamax</p> <p>prednison-endoxan/cyclofosamide-minrin-renitec-fosamax</p> <p>prednison-diflucan-minrin-renitec-fosamax</p> <p>prednison-endoxan-enbrel-octagam/gammaglobuline-minrin-renitec-fosamax-losec</p> <p>prednison-endoxan-octagam-minrin-renitec-fosamax</p> <p>In 2001-2002 an experimental treatment with Lutetium 77 (an internal radiotherapy was tried.)</p>	<p>10 mg prednison/day</p> <p>100 mg azathioprine/day</p> <p>0.1 minrin/day</p> <p>30 mg APD iv/ 3 months</p> <p>5 mg enalapril maleaat/day</p> <p>1000 mg calcium/day</p>	Stable. No pain, but energy has limits, yet "energy enough to do enjoyable things.	2/18/2009

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38	F		Approx. 2006			3 years of bi-yearly follow up with bone gammagraphy she was found to have more lesions in the ribs, liver and spine.	Ribs, liver, spine	None	None	Experiencing bone pain.	2/23/2009
40	M	1955	Jan. 2003, at death	45	48	January 2000 developed Pleuritis. After nine weeks of rest he got sick again with Pneumonia. Recovered, but had trouble breathing normally when exercising. Test showed lung capacity was decreased to 55%. Underwent multiple blood tests and biopsies. No diagnosis means no treatment. Physical condition slowly decreased and treated with antibiotics or prednisone. In July 2002 underwent an open lung biopsy. Biopsy showed no cancer or asbestos. January 2003 was given one gram of Prednisone treatment.	Lungs, heart, brain	Antibiotics, prednisone	n/a	Deceased	2/4/2009