

July 9, 1998

MEMORANDUM TO: SUZANNA VALDEZ  
Deputy Chief of Staff

FROM: MEREDITH MILLER  
Deputy Assistant Secretary for Policy, PWBA

SUBJECT: List of "Horror Stories" on Remedies

Attached is a list of cases prepared by Families USA that demonstrate the lack of adequate remedies under ERISA. Several of the parties involved in these cases may be able to present particularly compelling stories about how they were harmed by decisions by managed care entities, and then unable to be adequately compensated through litigation. Specifically:

Corcoran v. United Healthcare, Inc.: Mrs. Corcoran has appeared as a witness at several Congressional hearings to testify about the loss of her second child due to her plan's refusal to provide hospitalization or adequate in-home nursing care during her second high risk pregnancy.

Kuhl v. Lincoln National Health Plan of Kansas City, Inc.: Mrs. Kuhl could discuss the difficulty her husband experienced in obtaining specialized heart surgery at hospital outside the HMO service area, and her inability to sue for compensatory damages in state court due to ERISA.

Andrews-Clarke v. Travelers: Mr. Clarke, a severe alcoholic, committed suicide after his plan repeatedly denied his psychiatrist's requests for extended in-patient care. He left behind a wife and several young children. Mrs. Clarke's wife sued in federal court but her remedies claim was preempted by ERISA. The judge's opinion, in which he harshly criticized the inadequacy of the ERISA remedies scheme, has been widely cited.

Please let me know if you need any additional information. Thank you.

Attachment

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## COURT CASES EMPHASIZING ERISA'S LIMITATIONS

### I. Federal Appellate Decisions:

**BEDRICK v. TRAVELERS INSURANCE COMPANY (4th Cir. 1996)**  
93 F.3d 149

Ethan Bedrick was born with severe cerebral palsy and required speech therapy and physical therapy to prevent contraction of his muscle tissues. In April of 1993, Travelers Insurance Company terminated the speech therapy and severely restricted physical therapy when Ethan was 14 months old. When Ethan's father threatened to sue, the insurance company reviewed the decision. The insurance company concluded, without updating Ethan's file or consulting with his physicians, that intensive physical therapy would not result in what the insurance company described as "significant progress" for Ethan.

In its ruling in 1996, the Fourth Circuit held that Travelers' decision was arbitrary and capricious because the opinions of their medical experts were unfounded and tainted by conflict. The court observed that neither the insurance plan nor the company's internal guidelines required "significant progress" as a precondition to providing medically necessary benefits. "It is as important not to get worse as to get better", the court noted. The court noted that "the implication that walking by age five ... would not be 'significant progress' for this unfortunate child is simply revolting." (page 153)

ERISA left the Bedricks with no remedy to compensate Ethan for the developmental progress he lost during the three years and more that his parents had to litigate the benefit denial by Travelers. The Bedricks' state law causes of action were eliminated due to ERISA.

**CORCORAN v. UNITED HEALTHCARE, INC. (5th Cir. 1992)**  
965 F.2d 1321

Mrs. Corcoran was in an employer-sponsored health plan using Blue Cross as administrator and United Health Care handling utilization review. Mrs. Corcoran was pregnant and had a history of pregnancy-related problems. Although her own doctor recommended hospitalization, United Health Care denied that hospitalization was medically necessary and did not pre-certify a hospital stay. Instead, 10 hours of daily in-home nursing care were authorized. When the nurse was not on duty, the fetus developed problems and died. The Corcorans had no remedy for damages against United under ERISA. The Corcorans' claim for state damages were eliminated due to ERISA.

**CANNON v. GROUP HEALTH SERVICES OF OKLAHOMA, INC. (10th Cir. 1996)**  
77 F.3d 1270

Ms. Cannon was diagnosed with eublastic leukemia. She received chemotherapy

# NATIONAL PATIENT ADVOCATE FOUNDATION

A National Network for Healthcare Reform

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Newport News, VA 23606 1-800-532-5274

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TO: Brandon Hofmeister

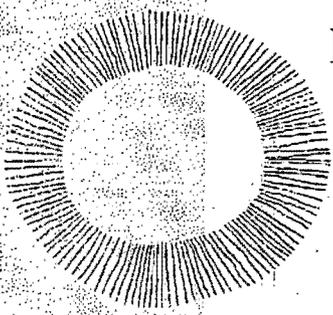
FAX #: (202) 456-5557

FR: Nancy Davenport-Ennis

No. Of Pages (including cover sheet): 36

Please find attached a summary of our cases in both our legal and managed care networks. Please call if you need additional information.

You may access our websites @ [www.patientadvocate.org](http://www.patientadvocate.org) OR [www.npat.org](http://www.npat.org) if you wish to know more about our organizations!



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July 16, 1998

**Marcy Davenport-Ennis**  
*Blindling Executive Director*

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**Thomas Sunonson**

The Honorable Bill Clinton  
 President of the United States  
 The White House  
 1600 Pennsylvania Avenue  
 Washington, D. C. 20500

Dear President Clinton:

As a national patient advocacy organization whose singular mission is to resolve insurance issues confronting cancer patients nationally, our organization receives referrals from every voluntary health agency in the nation and the major cancer centers. Additionally, we are identified by NCI in the "National Organizations that Offer Services to People with Cancer and Their Families" publication.

We serve patients through our National Legal Resource Network and our National Case Managers Network as we resolve expedited hearings matters, pre-authorization issues, denial of access through geographic redirection or financial refusal to fund the therapy prescribed and billing disputes. Attached are a few of our working summary notes on patients in our two networks: legal and managed care. These notes surely reflect that a Patient Bill of Rights that does not address liability of the plan when patients are in ERISA programs will result in very diminished improvements for our citizens in resolving health care disputes with their providers.

Our cases overwhelmingly reflect the need for reform in the following areas:

- External, expedited hearings by specialists in the disease related areas
- Requirement for reviews in strict, specific time periods to accommodate the medical indication of immediate care prescribed
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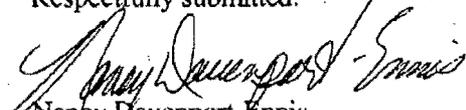
If names of specific patients are needed, please contact us.

Enclosed are our cases and a summary of cases recently provided to us by the United States Department of Labor reflecting consumers who sued their plans only to be informed that our current ERISA law provides no vehicle for remedy. Additionally, I have enclosed a Memorializing Resolution that our organization is presenting in each of the state General Assemblies urging Congress to make regulation and enforcement of ERISA a responsibility of the United States Department of Labor, State Attorney General and State Insurance Commissioner to insure timely responsiveness and equity for the individual consumer caught in the ERISA system.

We lend our full support to the Democratic version of the Patient Bill of Rights, though we

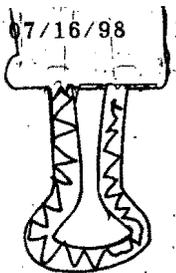
regret that it currently has no provision for funding for the patient portion of Clinical Trials costs. We do encourage that Clinical Trials funding be addressed when the Bill is reported out for review.

Respectfully submitted:



Nancy Davenport-Ennis  
Founding Executive Director

cc: Vice-President Al Gore  
Senator Thomas A. Daschle  
Congressman John D. Dingell



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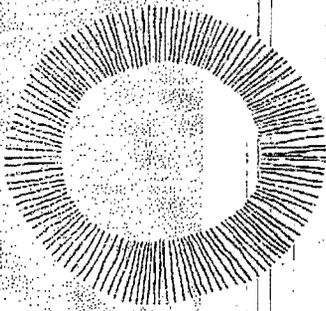
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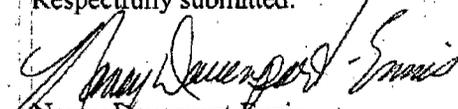
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cc: Vice-President Al Gore  
Senator Thomas A. Daschle  
Congressman John D. Dingell

National Legal Resource Patient Referrals  
Sheldon Weinhaus ProBono Director

Source	City	ST	Employer	Insurance	Type of illness	Problem	Resolution
Internet	Chicago	IL	unknown	BCBS, IL	Basal Cell Carcinoma	4/21 Pt called, stated ins co trying to cancel pol. Stated all family members have experienced some type of ca. He is concerned that if they cancel the pol he might not be able to obtain another pol. esp since the recurrence of ca is likely because of family history.	I explained that most co's will research for pre-cond if pt dx shortly after pol eff. (Oct 1, 97) pt dx 3rd wk March, 98. 4/28 fx'd to Art Gorov as consult only. 4/29 Art states that he wants \$750.00 to review cases from now on and if retained for service, the \$ will be deducted from the retainer.
Anderson	Houston	TX	Texas Retirement System (School Teacher)	Prudential (PruCare)	Duadonal Cancer (took pt of pancreas)	4/3 pt contacted PAF needs referral to MD Anderson Ca Ctr. Hooked to feeding tube. Ins co does not want to pay for MD Anderson pancreatic specialist. Pt leaking pancreatic fluids, only to be on tube for couple of wks, now been 14-15 wks	N D-E s/w many phys @ Methodist hosp, MD Anderson, Prucare med dir, deputy comm for HMO's, local press. Phy's refused to give referral. Pt losing weight daily; down to 73 lbs. Urgent that she rec tx @ MD A. Gave file to Cindy Leiferman Pt moved to MD Anderson & rec'g tx, gaining weight. <b>Resolved</b>
Called 800# factory	Calabasas	CA	Kaiser	Kaiser	Ovarian Cancer	5/11, pt called PAF, stem cell transplant denied altho Kaiser phy stated she was a good candidate. HMO stated she had had too much cisplatin; protocol 4 trn didn't use cisplatin. They were concerned that she would have neuro toxicity. Pt had prior radiation, intragastric toxicity. City of Hope was going to use a different drug. Bottom line, pt doing fine.	5/19: snt pkt to pt. Mark Heipler has been recommended by a neighbor, Judge John Doyle and by a law professor @ Pepperdine Univ, Carol Chase. Played telephone tag w/ Mark several times. Finally snt fax 6/15 <b>Pending: fu sch 4: 6/16</b>
	Viola	IL	Modern Woodman of America	Reliastar PPO (North Western National Life)	Mantel cell lymphoma: CMV, now on IV antibiotic.	S/w wife 5/4: As of May 8, Wednesday if he doesn't return to wk full time he can not come back to work. (4 children: 3,5,7,9) he is mechanic, wk almost 5 yrs w/ company. Filed complaint w/ EEOC.	Snt file to Mark DeBofsky. Mark stated that since the phy hasn't released pt to return to work, there isn't anything he can do. He also stated that the pt was aware of that but that the wife was so upset that she had been pursuing every avenue possible. S/w wife. states yes they did speak w/ Mark so she understands situation. 'Plz help find a job!..^') <b>Resolved 6/3</b>
Mr Faber, head of Ca	Indianapolis	IN	policy holder, husband wks: Sarco (scrap metal co)	Trustmark	Ovarian cancer	5/22 husband called. Pt in hosp having treatment. Ins. Denied bmt	referred case to Cynthia Leiferman, Esq. 6/12 I msg 4 c/b @ CL ofc. <b>Pending: fu sch 4: 6/15</b>

07/16/98 14:49

757 873 8999

PATIENT ADVOCATE

004

National Legal Resource Patient Referrals  
Sheldon Weinhaus ProBono Director

07/16/98 14:50  
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Source	City	ST	Employer	Insurance	Type of illness	Problem	Resolution
Website	Locust	NJ	Am Home Prod. Charles Brennan, policyholder, retired	Empire Blue Cross (NY)	non-Hodgkins lymphoma	husband called Paf 6/8/98: ins denied coverage 4 FDA approved clinical trials - states experimental, not covered; has pd 82K in bills, still owes 134k. Dr. Burzinski increased his fees several times after pt was in the program.	Rec'd consideral amt of info from Mr. Brennen. (mk out of ofc 6/10/& 11) Referred case to Sheldon Weinhouse 6/12. SW called, req. to refer to Mark Scherzer in NY (Stated he didn't want to touch it) Mk fx'd info to MS. He is in mtg & will c/b on Mon. <b>Pending: fu sch 4:6/15</b>
Home	Yonkers	NY	unknown	unk	Breast Cancer	6/3, Pt called PAF, needs help w/ job discrimination. Sever harrasment from supervisor. Pt has documentation	6/5, Mk s/w pt, req concise documentation of occurrences & signed consent form. Snt pkt. Pt states she is afraid of being around person @ wk because of the constant harrasment. Advised her not to discuss anything w/ this person unless someone else is with them of her (the pt) choosing; not to argue w/ her, that it is the other person's pblm not hers. Pt was made to feel like she was being punished & that she & her phy had made up the story re her dz. 6/16, mk ref to Susan Slaven & s/w pt. pt states she rec'd pkt & is wkg on document for us. 6/17: John Grasso, Intern w/ atty c/b; info rec'd but unable to reach pt @ this time. Mk will have pt contact their ofc. <b>Pending: fu sch 4: 6/18</b>
Person Barbara Jones	Joliet	IL	Unemployed	Uninsured	Brain Tumor	6/1: pt l msg: PAF c/b 6/3, states disability cut off; said not notified, trying to get reinstated	need to refer out to atty, ck w/ Sheldon. <b>Pending: fu sch 4: 6/8</b>
Andy, RN AMTUNIC	West Suffield	CT	True Green Chemlawn	Cigna Health Care (Healthsource, Provident)	non-Hodgkins Lymphoma	mk s/w Pt 6/4/98, states ins co denied transpant, after stem cell collection because his marrow was clean; they said he was in remission so they wouldn't apr.	Pt 2 prepare appeal ltr & fx 2 Kelly Wells @ Hlthsource/Prov by fx in am; cc 2 me; snd'g overnite benefits bk & consent fm. Contacted R. Carter & fx'd info. RC 2 call pt tonite. 6/7: s/w R.C. @ Bd mtg, he will let me know how things are progressing w/ pt. <b>Pending: fu sch for 6/11</b>

National Legal Resource Patient Referrals  
Sheldon Weinhaus ProBono Director

07/16/98 14:51

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PATIENT ADVOCATE

006

Source	City	ST	Employer	Insurance	Type of illness	Problem	Resolution
me	Evanston	IL	Not wking @ present	Celtic Life	Breast Ca w/ mets to brain, lungs, needs grammanice for ca-cells: in br. Has had non stop tx since Feb 91	4/9 pt called, s/w BH, ins co is going to drop @ end of April. Co. issued policy in error but pt has had pol for approx 8 yrs. She purchased it from brother as group of one. Pol states must be employed in order 4 pol to remain in force. States she has lost her jobs because of poor performance as a result of chemo.	per ND-E instruction, refer to Art Gorov. Art states, no job discrimination at all. However, there may be some serious coverage ?'s which he could not resolve without seeing the entire policy or policies involved. He would require a substantial deposit before further involvement. Spoke w/ pt, states she doesn't have \$ so she will not pursue at this time. <b>Resolved 4/22.</b> 5/21: Pt stated she has heard from an atty. formally w/ an insurance firm, who has offered to assist her @ no chg.
an rger, Atty Chicago Mike older.	Schiller Park	IL	Ameritech, phone co 25 yrs	Rush Prudential HMO	Ovarian Cancer	BMT Denied	Pt states was approved for eval @ Loyola Hosp but then denied for BMT there because it was out of network. Sec & 3rd denial was because of plan language: "experimental". 4/28/98, I msg 4 pt. Need req'd info asap. Fx'd info on hand to Art Gorov w/ note additional info will follow when rec'd. 04/29/98, spoke w/ A Gorov. wants above req'd info & \$750.00 to review case and will deduct from retainer if she decides to use him. Passed info to Nancy D-E. 4/30/98 per pt, she has decided against having BMT after speaking w/ several patients. She will discuss alternative care w/ her phy. Resolved 4/30/98
it'l mphoma soc., roline	Yardly	PA	disabled; Wk'd 4 Avalon Commercial, co has closed	Unum Life	Non-Hodgkins Lymp; Avascular necrosis caused by prednisone & chemo	wife called 4/14: states pt had pol 30+ yrs, no notice of cancelation. Canceled because he wasn't seeing Dr. Freundiech or getting tx. Disability was denied, also. Wife states pt can't raise arms up or bend over, is crippled.	wife states never rec'd copy of policy. She is going to try to obtain copy. Pt saw phy for 5 yrs but nothing has helped him. 4/28 I msg for wife to c/b, need denial ltr & plan doc. Fx'd info to Rich Carter <b>Pending</b>

National Legal Resource Patient Referrals  
Sheldon Weinhaus ProBono Director

Source	City	ST	Employer	Insurance	Type of illness	Problem	Resolution
Insurance	Smiths Grove	KY	Medco Center	Admin. Enterprises, Inc.	Breast Cancer	Needs help with obtaining insurance coverage and/or help with existing bills.	Pt to send log of creditors, amts pd and bal due. Snt pkt w/ consent form to be returned w/ information. She is to ck w/ State Comm. Ofc for insurance pool and make application. Ok to ck w/ Derry about policy. (Pt.ca still active) 6/3/98 rec'd info fr pt. Fx'd to Rich Carter for review. <b>Pending: fu sch for 6/5</b>
Cancer care counselor	North Bergen	NJ	Post Office	unk	Colon Cancer	Pt req job discrimination assistance. States she wants 2 wk & there is plenty of wk 4 her 2 do. Ten of her fellow employees signed a statement that there was plenty of wk. 4 her 2 wk full time. She was out of wk 1/25 thru 3/23. Postmaster had heart attack. OOF in chg, Thomason, told her she could only wk 6:00 to 12:00 so she only wkd 6 hrs. When postmaster was there she wkd 9:30 to 6:30, full time. 6 hrs is not enough wk for her. States Thomason was very arrogant, rude, no compassion, & upset because she didn't obey him. She has used all sick time, vacation time & fellow employees gave her some of their time. She went to the union & is in step 2 of grievance. EEOC complaint mailed.	Refer to Arlene Groch, ESQ.

07/16/98 14:52

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PATIENT ADVOCATE

007

National Legal Resource Patient Referrals  
Sheldon Weinhaus ProBono Director

Source	City	ST	Employer	Insurance	Type of illness	Problem	Resolution
Cancer ire	San Antonio	TX	none	Medicaid	Non-hodgkin's lymphoma	Needs help with disability denial and appeal denial. Patient has handled everything herself to this point.	(4-7-98) Spoke with Patti @ Dr. Smith's office. Patient to take all info. to office and have Dr. send letter requesting that they pull her file and review his last two letters. (4-15) Pt states she mld all info. Referred case to Cindy Leiferman in TX. She called today and stated that she has spoken w/ Pt's phy after many tries and discussed him re-submitting a more emphatic letter. She will get back w/ me on this case as soon as she hears back from him. 5/27/98
AT wsletter	Phoenix	AZ	none given	Cigna	Breast Cancer	Wants help getting coverage for stem cell that has been denied by insurance carrier. Wants attorney to help her.	(4-14-98) Spoke with Joann Mundrlok at Cigna. She will send copy of appeal letters (by Dr. Taylor). She states financial coordinator (Sylvia) is also working on denial. Updated patient by phone. Nd to wait for grievance to complete. 6/2 spoke w/ Cindy Leiferman earlier about case/ is willing to review. snt by fx today. <b>Pending: fu sch for 6/5</b>
Me	Lemont	IL	Unemployed	The Guardian Physicians Health Serv	Breast Cancer	S/W pt 4/21: fired March 26, 98; ins cancelled 4/1/98. Pt still had 50 hrs comp time, 55 sick days, & 3 personal days. Stated chng in mgm't caused pblms. Pt wkd w/ mentally ill & retarded pts. Lost job while rec'g chemo. Under pressure signed pt's names 2 documents.	requested concise documentation fr pt. Info came by fax but unable to read. Req'd typed document. Rec'd info fr pt by mail. S/w pt. States she is in process of reconstruction surgery. The original surgeon started when she had The Guardian. Now that she has had to change to her husbands pol, BCBS II, HMO will not allow her to complete the process w/ her phy. & are sending her to a phy in the ntwk. Pblm: the new phy doesn't do the same type of reconstruction so he can't complete what the orig phy started. She is caught in the middle. Mark DeBofsky thinks she has a case re: job, & will research pblm w/ health ins. Pt on vacation for nx 2 wks. <b>Pending fu: 7/8/98</b>

07/16/98 14:52

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01/97	BMT newsletter	Slidell	LA		Champus Tricare	Breast cancer	Ins Denied BMT	Ref. to Jo Lynn Slama 8/25-has spoken w/pt. requested pt forward materials concerning request for preauthorization together with med records. Upon receipt, Atty. will review mater and will be back in touch w/ pt concerning att recom. 10/3-in process of collective evident next admin appeal. Does not have metastatic which is basis for denial. 1-15-submitted a request for Hearing and request for reconsideration to ins. (next level of admin appeal.) Pending resolution
01/97	ACS	Athol Springs	NY	Deceased Husband's Insurance/ Lakeshore Central	BCBS	cancer of uterus	wants to be seen by dr. out of area; ins. won't pay; Ref. to Robert Koegel	Told PAF 8/22 by phone that Pt. probably has legal right to require health insurer to pay for opinion from out-of-area health provider, but would look at policy, if forwarded to confirm. Advised by phone several days later it would be. It hasn't.
01/97	Diane Lamb	Chapel Hill	TN	Leader Indus.	BCBS	Multiple myeloma	Ins won't let go to same dr.	Resolved: Hired own attorney, <i>deceased</i>
01/97	None Given	Lebanon	VA	Russell Country Medical Center	Trustmark; ERISA	Breast Cancer	Denied BMT	Resolved: Ref. to Ed Connette 8/25. 9/5-Coverage was approved. Pt is at Duke receiv HDC right now.
01/97	None Given	Milwaukee	WI	FlexBen Corp.	BCBS CompCare; ERISA	Ovarian cancer	Ins. not covering stem cell transplant	Resolved: Ref. to Art Gorov; 9/11 Atty review materials; Awaiting copy of complete coverage booklet/handbook and any letters receive from carrier and any correspondence. Med. College Wisconsin agree to do stem cell transplant be on their fund raising.
01/97	BMT Center	Lincoln	NB	Fleming Foods	Retail Wholesale and department store international union; ERISA	Multiple myeloma	stem cell transplant denied	9/18-Hired Rich Carter and Homer Reynolds. Faxed total cost to Rich per his request. Rich reassured him that he had written letter to ins & is speaking w/ their lawyers & will do his best to get it paid for.
01/97	ACS	Highland Park	IL		Conn. Nat'l life Ins.	Breast Cancer	Asked to sign retroactive rider by ins.	Resolved: Pt. decided not to use an attorney

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01/97	Gay Bianchi	Warrington	PA	Bertz Dearborn Company	Prudential; ERISA	ovarian cancer	Ins. deny stem cell transplant	Resolved: Ref. to Homer Reynolds 8/19/99 reviewed tests and it is not in best interest to pursue HD chemo. They will allow appeal to proceed, but will be taking no aggressive steps expedite or influence any outcome.
01/97	Irio Transplant	Midwest City	OK	A.H. Metal Fabricators	Healthcare of OK	liver failure due to Hep. C & or sec. to alcohol	Denied 2 times for liver transplant	Resolved: Completed level II grievance, attended hearing of Grievance panel. Anticipate seeking injunction in ct in event of a denial. 10/8-Ins. for transplant-subject to confidentiality clause placed on transplant wait list, receive liver so-
01/97	M.D. Anderson Speech	Waller	TX	None	Medicaid	terminal prostate cancer	Not sure if Medicaid will be part of State HMO; trying to go to M.D. Anderson for treatment	Resolved: -PAF called PAF attorney. Asked to walk him through the appeals steps he needed take with Medicaid. Could not get in touch w-
01/97	Women's fund for HER in Houston, TX-newsletter	Houston	TX	Self-Employed	Trustmark	endometriosis/numerous other procedures	Ins. only pay for one procedure per incision and working from a price list from 1989.	Resolved: After Ref. to 2 PAF attorneys and case worker, determined that PAF would not be able to help. We specialize in cancer, and this was told to patient.
01/97	ACS	Lockport	NY	Lockport City School District	BCBS of Western NY	Breast Cancer	Need help w/ coverage of medications	Ref. to Robert Koegel 9/22. Counseled pt. husband to followup to get the problem solved; agreed he would solve the problems. Pt. must negotiate settlement of bills w/insurer. Resc-
01/97	MD Anderson	Kennedy	NY	Agway	Unicare ERISA	Strom's Cell Cancer	Wants to go to Brazinski Clinic. Insurance has denied this request.	Ref. to Susan Slavin 10/19-11/12-Tried to contact Ms. Clark at home and work. Unable to speak directly. Informed that pt and husband were receiving treatment. Suspended activity.
01/97	Leukemia Soc.	Cambridge	OH	Unemployed	Uninsured	Chronic Lymphocytic leukemia	\$40,000 in debt. Trying to secure Medicaid cared. Has been denied.	Referred to Debra Bass 10/14-11/4-Debra did considerable research concerning case, but pt too far away for her to effectively represent V. told by Rick Clay, pt case worker, that he had list of attorney in his area who frequently take these types of cases on a contingency fee ba-

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01/97	Y-me	Lafayette	LA	Unemployed	Midwest National Life Ins. of TN	Breast Cancer	Wants to know if covered by insurance even though she cancelled it after she was told she was not covered.	11/97-Alicia Dendana wrote letter to pt. to explain that there would be nothing she could do to help patient. Resolved.
01/97	American Health Mag.	Buffalo	NY	Home Properties of Western NY	Independent Health	Breast Cancer	She is deceased. Son wants to resolve insurance issue.	Ref. to Robert Koegel. Advised son to finish informal grievance-go through State Insurance Commissioner. Son realizes nothing to be done through suit. Resolved.
01/97	Lymphoma Found	Los Angeles	CA	U.S Airways	Kaiser Permanente	Lymphoma Cancer	Want to get referral to be seen at City of Hope.	Ref. to Mark Hiepler 10/21-Wrote letter to pt. Never responded. Suspended activity
01/97	Coping Mag.	Champaign	IL	Bob Wallace Industrial	Health Alliance	Breast Cancer	Ins denied HDCT/stem cell transplant	Ref. to Art Gorov 10/29-called atty. bro, called left message w/ both, no response. 11/3-suspended activity. 12/3-going w/ another atty. No more PAF activity.
01/97	Jill Rosenbaum-CBS news	Whitestone	NY	Dolan & Traner sub. of Dupont	U.S. Healthcare	fibro-mylacia	Ins. denied subcutaneous lidocaine infusion treatment	PAF referred her to call Mark Scharzer or Scott Reimer. This would not be a PAF referral. Resolved.
01/97	Brain Tumor Society	San Ramon	CA	Rabco Enterprises	Kaiser-Permanente	brain tumor	Wants referral to another hospital	11/12-PAF advised pt to get definite yes or no from neurosurgeon before any action can take place. 12/97-Ref. to Gary Tysch-Pt. filed formal grievance w/Kaiser. Mailed complain form to f w/ CA authorities. Will contact if any problem
01/97	Roberta Cahoon-Social worker	Superior	WI	Dental Assistant	American Medical Securities/None	Brain Tumor	Ins. dropped her because did not have certificate in hand when diagnosed.	After reviewing w/2 PAF attorneys, advised pt no claim. No further activity.
01/97	Dr. Avery	Powell	TN	Post Office	Mail Handlers	myelodisplasia <i>see Lymphoma Disease is not Life threatening</i>	Ins. denied BMT	Ref. to Mr. Cheatham- Atty. is consulting w/ pt. doctor and researching details of case. <i>ND</i>
01/97	BMT newsletter	Gallen	MI	Eagle Technology	BCBS of MI	Leukemia	Ins. denied BMT	Ref. to Rich Carter, He has spoken with pt. PAF called pt to have him call Rich Carter.
01/97	Y-me	Tuscon	AZ	U. S. govt	Tricare	Breast Cancer	Job discrimination	Ref. to Deneen Peterson; 3/3 letter informed pt that atty. is not accepting any new insurance coverage cases at this time. Gave 2 other atty who may take case.

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01/97	Brain Tumor Foundation	Tonganoxie	KS	Ret. Teamsters Union	Central State	brain tumor	Trying to get disability life insurance.	12/10/97-Ref. to Sheldon Weinhaus-told that needed dr. to say that had brain tumor when retired. Need to get 60 extension on appeal. Would have a case, but need this info from D. PAF called pt. She said she'd do this for husband. Call if need help.
01/98	NABCO	Memphis	TN	Memphis City Schools	Prucare (Prudential) (ERISA)	Breast Cancer	Pt wants referral to breast cancer specialist. One she chose is out of network.	Referred to Rich Carter 3-17-98. <i>Resolved</i>
01/98	Not given	Franklin	TN	Not given	Prudential Plus HMO ERISA	Breast Cancer	Ins. denied stem cell treatment	Sent information to Department of Labor for add to investigation of Prudential. They do not investigate individual cases.
01/98	Y-me	Chicago	IL	would not tell	would not tell	Breast Cancer	Job discrimination	Resolved: Ref. to Mark DeBofsky; Counselor to contact him when there was a change in the employment.
01/98	Friend	Vista	CA	Self-Employed	Blue Cross	Brain and Spine Tumor	Ins. denied treatment b/c used non-FDA approved treatments	Referred to Mark Hiepler. Needs \$2500 special eval 3-5-98.
01/98	Local Cancer Support	West Haven	CT	Local Telephone Company-Retired	U.S. Healthcare	Prostate Cancer	Ins. has denied proton beam radiation	Resolved: Patient found own attorney which is happy with. Has been approved for treatment.
01/98	NABCO	Memphis	TN	Memphis City Schools	Prucare-ERISA	Breast Cancer	Wants referral to breast specialist out of network	Ref. to Don Donati: informed that did not take case. Sent letter to pt. asking if she still need assistance, call PAF office.
01/98	Blood & Marrow Newsletter	Mesa	AZ	United Food & Commercial Workers	Southwest Service Administrators (ERISA)	AML	Insurance has denied BMT	Pt contacted Rich Carter 5 Mar 98 on their own.
01/98	Breast Cancer Foundation	Fl Wayne	IN	Kelley Chevrolet	Physicians Health Plan <i>HAD BEEN SUED 5 X'S AND LOST.</i>	Breast Cancer	Needs BMT. Insurance denies.	Pt has been to court twice; lost. Referred to Rich Carter. <i>Switched to India Comp. it PD.</i>
01/98	Leukemia Soc of Am	Stroudsburg	PA	Retired electrician	Uninsured	Multiple myeloma	Pt needs to get Medicare to pay. \$57,000. Needs stem cell trans.	Sent paperwork to Rich Carter 2-20-98. Ask for compassionate plea to get pt into Medicare clinical trials.
01/98	Friend	Zion	IL	Ameritech	Maxicare-ERISA	Breast Cancer	Needs referral to doctor who will do plastic surgery	Suspended Activity: Ref. to Art Gorov, when pt sends him plan language to review, he will start working on the case. Sent letter to pt. asking to mail plan language and let PAF office know.

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01/98	Leukemia Society	Houston	TX	Nct given	General American	Leukemia	Debt collection intervention	Resolved: Ref. to Robert Provan; 2/25-atty. v. letter to creditor asking that pt. no longer be contacted at work or otherwise harassed. Do not anticipate any further action being needed unless the harassment continues.
01/98	Gay Bianchi	Grand Rapids	MI	Seminary student/part-time church employee	BC of MI	Breast Cancer	Needs T-Cell transplant	Resolved. BCBS will pay for transplant is pt. to either Detroit or Ann Arbor for treatment.
01/98	Cancercare	Franklin	WI	Village Manor Nursing Home	WPS-ERISA	Breast Cancer	Job discrimination	Ref. to Marianne Robbins; Pt. retained atty on contingency fee basis to represent her in her c for discharge against her employer.
01/98	Ovarian Cancer Coalition	Little Rock	AR	Little Rock School System	BCBS of AR-ERISA	Ovarian Cancer	Needs \$6000 wk for fluids, reaching 1 mil cap.	Ref. to Scott Hickman; has tried to contact pt. letter to pt. 3/3, asking her to call PAF and up if she still needs assistance. Copy letter to a
01/98	Internet	Valhalla	NY	Westchester County	Pomco	Maxillary Sinus Adenol Carcinoma	Total Chg @ hosp \$35k, Ins pd \$11k, fam has pd some, bal owe \$23K	4/8/98 s/w Scott Riemer; will take case & get w/ us to updt asap. 4/15 s/w Felicia in Rieme. ofc, he is n/a so will fx memo., t/c fr SR states: s/w pt who stated hosp in process of neog. bil. msg 4 pt 2 c/b. 4/16 s/w Jerry (husband) 4 updt states bal is now down to 16,500. Pomco ins for W. Chester Co. Phillip Speziale is the ben. admin for the co. Co atty involved is Cashman wants to see if nego comes thru before SR ge involved and will c/b asap. 4/27 l msg 4 c/b. 4/29 same; 5/11 s/w daughter. neither parents @ home, states pblm s/b resolved on Wed. Pending
01/98	BMT Newswttr	Skokie	IL	Union (arcade business services)	Local 25 Union Health (ERISA)	Breast Cancer to ribs	Ins denied stem cell transplant - experimental.	Referred to Rich Carter 3-13-98; said he will consult w/ them. <i>Resolved: Ins. Trans. in April</i>

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1/98	Friend	Grant Pass	OR	ECS Composite	KMSB	CML	BMT Denied	pt called 3/6/98, as of 3/13 @ 3rd appeal level prior notes. 4/7/98: s/w Rich Carter, will take c. fx'd info. 4/15 Mk follow up: fx'd memo req'd u. s/w Kelly. Rec'd fx fr Kelly, R.C. s/w pt, she i. snd him info. 4/23 rec'd fx fr RC, pt to c/b; she ck w/ phy to see if he will be avail for an apoa. 4/27: s/w Kelly, doesn't think pt has responde. msg 4 c/b fr Kelly. is phy going to be avail?... 4 pt to call, re phy. 4/29 pt states she is wkg o. phy 2 be on stand by w/ a cell ph. Req'd her to stop immediately and get arrangements finaliz. hearing is schedu led for tomorrow. If she nee. my assistance, she'll let me know. Pending
01/98	American Cancer Society	Modena	NY	Spence Engineering	Not given	Hodgkins Disease	Employer wants her to take voluntary layoff. She said no.	PAF attorney willing to consult with pt, but PAF office cannot get in touch with pt (will send pt letter asking for better contact numbers) 4/8: m. s/w sec in atty's ofc. Req that she pull file & up. status of case. 4/27 snt fx req'g fu asap. No response. 5/15 s/w pt. states after speaking w. new manager & explaining what happened he straightened everything out for her. Everythin alright now. Resolved 5/15/98
01/98	Response Oncology: Gay Bianchi	Liverpool	NY	Lockheed Martin Integrated	Premier Health Network	Inflammatory Breast Cancer	3/19 William Mandeville called, Ins denied HD Chemo & Stem Cell Trn	3/19/98 referred to Woody Connette. 4/15 mk fx to WC for follow up. 4/27 mk fx to WC for fo up. WC states will c/b rx wk. WC has spoken another atty to affirm plan language. Will keep updated
01/98	BM Foundation	Las Vegas	NV	ABC Taxi	Sierra Health Options (ERISA)	Non-Hodgkins Lymp	Pt needs stem cell or bone marrow transplant. Insurance policy excludes organ transplant.	
01/98	Colleague, Dr. Bailey	Howell	NJ	Not given	no insurance	Colon Cancer	Pt didn't qualify for Champus; Inappropriate ireatment from VA hospital	Refer to Rich Carter; per R. Carter, family has hired an attorney. Resolved 04/23/98

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01/98		Williamstown	MA	Williams College	Pilgrim Harvard Health	Ovarian cancer	Job Discrimination Tenure Discrimination	04/16/98: I msg 4 pt to c/b, need dt fired, need referral from Sheldon Weinhaus. Referred to Warren Pyle @ 617-723-5500. L. msg for c/b 4/16. Atty Pyle no longer w/ firm. L/msg 4 c/b receptionist. Fx'd info & s/w atty. States he has exp w/ many faucilty @ univ. and exp w/ disai cases. He will take case... snt fx to PAF 5/7 to accept pt. have pt to call him. s/w Ms. Beretz. is delighted and will contact him.
01/98	Lymphoma Found	Kailua-Kona	HI	Retired: Fed Gov't, Dept of Defense, Merchant Marine	Kaiser	Low grade Lymphoma	Kaiser Phy avoiding pt's req 4 specific treatment. Pt has had oral chemo for 4 yrs. Retuxian was approved so he wants the tx however Kaiser deny's coverage. Actually, phy is against it, then for it, then against it again. He keeps going back & forth. When pt mentioned that the drup had been approved, the phy stated that he was not in the experimental busines.	4/21: pt to document activity & fax. 5/5: refer Mark Hiepler. Constance called stated Mark c not handle this case @ this time, esp since p Hawaii. Req'd referral to atty in Hawaii. 5/11: heard from Constance, phoned back & l. msg referred to Richard Turbin in Hawaii
01/98	Cancer care	San Antonio	TX	none	Medicaid	Non-hodgkin's lymphoma	Needs help with disability denial and appeal denial. Patient has handled everything herself to this point.	(4-7-98) Spoke with Patti @ Dr. Smith's office. Patient to take all info. to office and have Dr. letter requesting that they pull her file and rev his last two letters. (4-15) Pt states she mld ai Referred case to Cindy Leiferman in TX. She called today and stated that she has spoken Pt's phy after many tries and discussed him re submitting a more emphatic letter. She will g back w/ me on this case as soon as she hear back from him. 5/27/98

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01/98	Cancercare Brenda Waiker	North Bergen	NJ	Post Office	unk	Colon Cancer	Pt req job discrimination assistance. States she wants 2 wk & there is plenty of wk 4 her 2 do. Ten of her fellow employees signed a statement that there was plenty of wk. 4 her 2 wk full time. She was out of wk 1/25 thru 3/23. Postmaster had heart attack. OOF in chg, Thomason, told her she could only wk 6:00 to 12:00 so she only wk'd 6 hrs. When postmaster was there she wk'd 9:30 to 6:30, full time. 6 hrs is not enough wk for her. States Thomason was very arrogant, rude, no compassion, & upset because she didn't obey him. She has used all sick time, vacation time & fellow employees gave her some of their time. She went to the union & is in step 2 of grievance. EEOC complaint mailed.	Refer to Arlene Groch, ESQ.
01/98	Y-me	Evanston	IL	Not wking @ present	Celtic Life	Breast Ca w/ mets to brain, lungs, needs grammanice for ca cells in br. Has had non stop tx since Feb 91	4/9 pt called, s/w BH, ins co is going to drop @ end of April. Co. issued policy in error but pt has had pol for approx 8 yrs. She purchased it from brother as group of one. Pol states must be employed in order 4 pol to remain in force. States she has lost her jobs because of poor performance as a result of chemo.	per ND-E instruction, refer to Art Gorov. Art si no job discrimination at all. However, there may be some serious coverage ?'s which he could resolve without seeing the entire policy or pol involved. He would require a substantial dep before further involvement. Spoke w/ pt, state she doesn't have \$ so she will not pursue at ll time. Resolved 4/22. 5/21; Pt stated she has heard from an atty, formally w/ an insurance fi who has offered to assist her @ no chg.

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01/98	Joan Burger, Atty fr Chicago w/ Mike Molder	Schiller Park	IL	Ameritech, phone co 25 yrs	Rush Prudential HMO	Ovarian Cancer	BMT Denied	Pt states was approved for eval @ Loyola H but then denied for BMT there because it wa of network. Sec & 3rd denial was because of language: "experimental". 4/28/98, I msg 4 pt. Need req'd info asap. Fx'd info on hand to Ar Gorov w/ note additional info will follow when rec'd. 04/29/98, spoke w/ A Gorov. wants abs req'd info & \$750.00 to review case and will deduct from retainer if she decides to use him. Passed info to Nancy D-E. 4/30/98 per pt, sh decided against having BMT after speaking v several patients. She will discuss alternative w/ her phy. Resolved 4/30/98
01/98	Nat'l Lymphoma Assoc.; Caroline	Yardly	PA	disabled; Wk'd 4 Avalon Commercial, co has closed	Unum Life	Non-Hodgkins Lymp; Avascular necrosis caused by prednisone & chemo	wife called 4/14: states pt had pol 30+ yrs, no notice of cancelation. Canceled because he wasn't seeing Dr. Freundiech or getting tx. Disability was denied, also. Wife states pt can't raise arms up or bend over; is crippled.	wife states never rec'd copy of policy. She is to try to obtain copy. Pt saw phy for 5 yrs but nothing has helped him. 4/28 I msg for wife to need denial ltr & plan doc. Fx'd info to Rich C <b>Pending</b>
01/98	Internet	Chicago	IL	unknown	BCBS, IL	Basal Cell Carcinoma	4/21 Pt called, stated ins co trying to cancel pol. Stated all family members have experienced some type of ca. He is concerned that if they cancel the pol he might not be able to obtain another pol. esp since the recurrence of ca is likely because of family history.	I explained that most co's will research for pre cond if pt dx shortly after pol eff. (Oct 1, 97) p 3rd wk March, 98. 4/28 fx'd to Art Gorov as consult only. 4/29 Art states that he wants \$750.00 to review cases from now on and if retained for service, the \$ will be deducted fr the retainer.

4/98 ? NY NY Disabled ?  
 1/98 Jan N.C. Restored her cases.

wanted Cash - we gave her all of our packet info.

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National Legal Resource Patient Referrals  
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Called	Source	City	State	Employer	Insurance	Type of illness	Problem	Resolution
01/97	None Given	Hollister	CA		Kaiser Permanente	adrenocortical carcinoma	To seek reimbursement for 2 evaluation visits that were done without Kaiser's approval.	2/18/1997-Mark Hiepler sent letter to pt. parent and advised them this is a medical malpractice matter. It would be more cost effective to have local counsel. contact your local bar assoc. referral to malpractice attorney.
01/97	None Given	Buffalo Grove	IL		Rush Prudential	Breast Cancer	Seeks home care After receiving BMT in 4-96. Rush Prudential, Matteson IL has also denied payment of her BMT bills. Ref. to Art Gorov.	Resolved
01/97	Barbara Groves	St. Louis	MO	Francis Howell School District	Gencare admin by BPA	Breast Cancer	Denied BMT @ MD Anderson	Now pursuing treatment @ Dana Farber through Clinical Trial. Resolved
01/97	None Given	Marlton	NJ				What to do after reach \$500k cap on health insurance	Ref. to Sheldon Weinhaus who ref. to John Crosby of Al. i.e. Contact lawyer or go on public assistance.
01/97	Memorial Hospital	Chatham	IL	U of Illinois at Springfield	Health Alliance	Breast Cancer	BC patient denied BMT.	We sought negotiated settlement through MCO. When that failed we transferred case to Art Gorov who won a court injunction for patient to immediately receive BMT.
01/97	None Given	Milwaukee	WI				Mother denied preauthorization for BMT.	Transferred case to Art Gorov. Patient has not returned calls. Was looking for atty. closer to home.
01/97	None Given	Jameston	NY		Uninsured	Leukemia	Company has put on part-time status	Ref. to Sheldon Weinhaus. She has found a job. Resolved.
01/97	Called 1-800 #	Glen Ellyn	IL	Unemployed	Medicaid	Pituitary tumor	Seeking care as unemployed divorced parent of 8 yr. old child.	Ref. to Art Gorov. Counseled patient to seek through social services. Resolved.
01/97	None Given	Houston	TX	Century Development	Great West; ERISA	Abnormal pap	Fired from job	Ref. to Howard Kamin. ADA violation as disabled victim or job discrimination. Case being developed. 9/15-Atty talked w/ pt several times requested certain documents back in May 1997 and haven't heard from her since. Resolved.
01/97	None Given	Fullerton	CA		FHP	Brain Tumor	Many problems on chart. Ins. com. will not act until 9/97. Ref. to Mark	9-8-97-Attorney received no response from patient attorney calls or letters to her.

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01/97	ACS	Smithfield	VA		Optimal Choice		Health insurance dropped her and 200 people w/o notice. Unable to get health insurance.	Ref. to Rich Carter-Spoke to pt for about 1/2 and review case, outlined law & options re: her case, does not have immediate problem: amount to be covered is still not clear, may have any problem at all, left it w/ her that if she has further ?'s she'll call. Suspend activity.
01/97	Dawn Drost	Elk Grove Village	IL	Elk Grove Park District	Maxi Care	Bi-polar	Job discrimination	Ref. Art Gorov. He supplied 2 public agencies patient to call for assistance. Resolved
01/97	Charles Weaver	Asheville	NC	Swannanoa Lumber Corp.	United Health Care of Minneapolis		Benefits language too restrictive.	No immediate action can be taken w/o compromise to patient. Resolved.
01/97	Trio Transplant	Los Angeles	CA		Gov't of Guam	obstruction of liver bioproducts	Malpractice suit. Physician misread tests.	Ref. to Mark Hiepler. Unable to contact pt. in USA. Resolved.
01/97	phone book	Hampton	VA	Veteran's Administration	Medicare-BCBS Trigon	prostate cancer	To get home oxygen to die in peace.	Ref. to Peter Sissman. 6/25-was able to get oxygen prescribed for patient. Resolved.
01/97	None Given		IN		Medical Mutual of OH	Breast Cancer	Denied BMT by insurance	Ref. to Rich Carter; Covered after appeal. Resolved.
01/97	Gay Bianchi	Blanchard	MI		BCBS of MI	Breast Cancer	BC patient denied BMT.	Ref. to Elizabeth Gleicher received BMT-res.
01/97	Lutheran Hospital	Rolling Hills	IL		Humana	Ovarian cancer	Insurance denying BMT	Ref. to Tom Shwab. Pt had her BMT and is progressing wonderfully. Resolved.
01/97	Y-me	Rochester	NY		Blue Choice	Breast Cancer	Dr. did not order mastectomy when lump was evident	Sent malpractice suit letter 7-10 and second to affirm our position 7-25
01/97	relative	Hope Mills	NC			Cervical Cancer	Debt	Ref. to Cliff Brisson; Resolved
01/97	BMT	Vienna	VA	Booze, Allen, and Hamilton	Prudential; ERISA	Ovarian cancer	Needs BMT: Ins won't pay for it. Ref. to Rich Carter	9/8/97-Appeal made; pending determination
01/97	None Given	Merrillville	IN		Prudential	Ovarian cancer	Ins. has denied stem cell transplant.	Ref. to Art Gorov; case resolved. Insurance do stem cell transplant. Resolved
01/97	None Given	Stamford	CT	Dolphin Management Company		Breast Cancer	Required HDCT	Ref. to Sheldon Weinhaus; received treatment resolved
01/97	Y-me	Manchaca	TX	Unemployed	Medicaid	Breast Cancer	Doctor did not drain breast	Sent malpractice suit letter 7-10 and second to affirm our position 7-25. Resolved.
01/97	Linda Sue Pinkston	Hope Mills	NC	Belk Service Center		Repetitive stress injury:	Let go from job after had surgery	Pt. given 3 lawyers names in Fayetteville sin was job discrimination. Resolved.

National Managed Care Referrals

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
07 Cancer Services	San Antonio	TX	Unemployed	Medicaid	Kidney Cancer	Medicaid will not cover supplemental-home oxygen.	12/12-Ref. to Jean Salazar-Pt will have nephrectomy at end-of-month. Dr. advised on manual exam he found mass in left flank. Her hematocrit is slowly dropping. Due to religious beliefs she will not accept blood transfusion. Has had no chemo
08 Y-Me	Tuson	AZ	unknown	Tri-Care(S.C.)	Br Ca/Full Mets	Job Discrimination	info fx'd to Denneen Peterson by Marianne West. MK needs to follow up to see if case has been resolved
09 Leukemia Society	Parkersburg	WV	unemployed	Medicare	Multiple Myeloma	Needs help securing lift chair	Ref. to Jean Salazar
10 Brain Tumor Foundation	Myersville	MD	None	Uninsured	Brain Tumor	Wants assistance getting SSI or SSN benefits	Ref.to Gay Bianchi- she said she would call and see what she could tell them.
11 Cancercare	Yellow Jacket	CO	Mack Tools	Cigna	lymphoma	Needs help determining if missed deadline to appeal claims insurance is denying	Ref. to Jean Salazar; mk called daughter on 4/28/98. States hadn't heard from anyone. Had gotten \$600.00 chair but took it back because parents couldn't afford it. I told her about ACS providing \$ and that maybe it would be applicable to use for the chair. She stated that dad could hardly walk and couldn't get up out of a regular chair. 5/18 l. msg. @ Cindy's home for updt c/b
12 ACS	Eureka	IL	None	Medicaid	lymphoma	Wants to know if she will have to pay full pymt to hospital	Resolved: PAF discussed situation and pt. said she would wait to see if hospital would demand pymt. If so, she will contact own attorney and media.
13 Not given	Richmond	CA	Graduate Student	Kaiser-Permanente	Breast Cancer	Wants a second opinion	Resolved: PAF referred pt. to Dr. who provided pt. with names of Drs. to help pt. her her own plan.

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National Managed Care Referrals

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	Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1	BMT newsletter	Darwood	MD	Kaynar Technologies	Maxi Care	leukemia	Son wants father to be moved back to hospital where he will get physical therapy instead of nursing home where he is now placed.	Resolved: Son has resolved situation w/ PAF counselling and advice.
14	ACS:NJ	Eggharbor Township	NJ	Female child; 6 yr old	Atlanta Care	Aplastic Anemia	Needs \$ 2 see dr @ children's hosp; philadelphia 100 miles w/ 4 other kids @ home; father mental brkdown, is in hosp;	Resolved:04/15/98;Ashley had bmt 1/14 & is doing great; sis was match; neighbors, church members all big help. Wkng on bills one day @ a time; very grateful 4 assistance.
15	Coping Magazine, Jan/Feb 98	Hinckley	OH		Healthstar of Ohio	Breast Cancer	rec'd ltr stating premium increase of 70% (\$244. To \$412.) Co pd \$15k of \$40K in chgs	info re: ins comm was faxed to daughter, Deb Morton. Mk needs to follow up to see if pblm has been resolved 5/26
16	Cancercare	Bronxville	NY	Don-Glo auto repair center	U.S. Healthcare	throat cancer	Help getting S.S.Benefits	Ref. to Jean Salazar
17	Coping Magazine	Smyrna	GA	Atlas Roof Corporation	BCBS of MS	Breast cancer	Does not know how much money she owes to ins.	Resolved: PAF referred to legal aid.
18	Transplant Receptient Organization	Bowie	MD	student	not given	Liver transplant	Ins. dropped from plan w/o warning b/c 21.	Resolved: PAF supplied information about contacting state ins. commissioner.
19	Wife	Milwaukee	WI	City of Milwaukee	Family Health Plans	Colon Cancer	Needs second opinion not within first opinion's office	Resolved: PAF referred to State Ins. Commissioner.
20	Candlelighters	Athens	OH	Ohio Univ.	Anthem	Hodgkins lymphoma	Ins. refuses to pay for 5 yr. checkup. Say it is preexisting.	Ref. to Jean Salazar
21								

07/16/98

15:03

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PATIENT ADVOCATE

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National Managed Care Referrals

	C	D	E	F	G	H	I	J
	Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
122	friend	Algonquin	IL	Unemployed	Medicare	Squamousal of Perianal area	Doctors will not treat her.	Resolved: PAF provided number to Best Doctors to find doctor who will treat pt.
123	ACS:Albany NY Kris Brindel	Kinderhook	NY	Lindenwald Farm & Corp	Empire BCBS Tradition Plus	Breast Cancer	Ins not paying for mamogram	Resolved: 04/08/98; 5 claims are outstanding but will be pd;co has agreed to pay for mamogram 1 per yr.
124	Cancer Care	Franklin	WI	Village Manor Nursing Home	WPS (HCNPOS)	Breast Cancer	Pt experienced job discrimination for work absenteeism, excuses.	Insurance cancelled 31 Jan 98. Scheduled for reconstructive surgery 3 Feb 98.
125	Cancer Legal Resource Center	Deerfield	FI	Cleans Houses	Physicians Health Plan	Breast Cancer	Insurance says she has preexisting condition	Resolved: PAF provided number to State Insurance Commissioner.
126	Leukemia Soc. of America	Goodwater	AL	USDI	Uninsured	leukemia	Needs to be seen by doctor	Ref. to Jean Salazar
127	friend	Kerrville	TX	Unemployed. Previously employed by Exxon Service Station	No insurance	Leukemia	Needs financial assistance to pay for doctor bill	Resolved. PAF negotiated with Dr office to hold bills until SSI approval. SSI will be retroactive to 3 mo.
128	Brochure	South Wilmington	IL	RR Donnally & Dewight	John Deere	Brain Tumor	Needs help w/ Insurance John Deere 'giving them a hard time'. Mk needs to speak w/ Deb to see specifically what pblms she is having	Dawn gave # to State Ins. Comm. States wife will c/b if additional help is needed. 4/28/98 MK l. msg. 4 Deb to c/b asap. Need to know if pblm has been resolved or if she needs more help. 5/18:l.msg w/ daughter to give Deb my # & to l.msg.4 me tonight on ans machine.5/26 s/w Kelly, daughter. Folks are at phy getting chemo. She will have mom call me today or tomorrow. Explained that in order to assist her I need additional info.

National Managed Care Referrals

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1 Brain Tumor Society	New York	NY	ABC Inc.	Health Plan Ins	Brain Tumor	Wants 2nd opinion to out-of-network doctor	Resolved. PAF advised pt to re-examine ins policy -- Pt discovered new policy will cover 2nd opinion dr.
29 ACS	Greenwood Lake	NY	Sandy Hill	PHS-Guardian	Breast Cancer	Insurance company refuses to pay to fix plastic surgery. Implant is rippled, deformed, may be defective.	Resolved: (4-8-98) Spoke with patient; she will fax approval letter & will call when corrective surgery has actually taken place and bills paid.
30 Unk	Hollywood	FL	wks 4 Healthplan of Florida	Healthplan of Florida	Leukemia	No \$ for BMT; ins denied/out of ntwk	Resolved: (04/08/98) Ins accepted BMT out of network. Pt needs apr ltr: 1 msg 4 Loraine Reddig. Pt staying w/ parents until trn completed
31 Internet	Piedmont	CA	disabled	Healthnet (Alta Bates Medical Group)	Metastatic Melanoma	Wife called 3/15: Per Dawn notes: 01/98, tumor recured, pt wants to go to MD Anderson & is ready 4 surgery. Ins giving hard time.	Dr. Jeffrey Wolf agreed to treat pt. Resolved per ND-E 4/22
32							

07/16/98 15:04

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PATIENT ADVOCATE

National Managed Care Referrals

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem:	Resolution
33 Cancer care	New York	NY	Costume Designer United Scenic Artists	Aetna	Prostate Cancer	PCP referred to Oncologist out of ntwk, told was covered @ 100%. Nds 2 find out if he is covered. Starting chemo soon, what is covered?	pt called 3/11, per Dawn: Ins not paying for anything out of ntwk. PCP Dr. Tamarin intervened. Ins to pay for referral doctor. Resolved: dt unknown. Mk
34 unsure		NJ			Colon cancer	Dr. Santoro's uncle died of colon cancer. He was a veteran and the vets hospital was no help. Time line tests not run and aunt is stuck with large bills.	(4-15-98) Issue was resolved by patient with help of DAV.
35 Candle-lighters	Elgin	IL	Father: Jeff works for Union Dry-Wall as installer.	Painter's District Council #30, Health & Welfare Fund	Leukemia	Insurance denied BMT donor expenses. School Social Worker, Carol Nightingale, helping document appeal. 5/26 per Carol, bal remaining fr BMT: 300 to 400 \$'s. Donor Harvest: \$6,470.70 and donor testing: \$1,636.00	Gave patient number of consumer complaints and inquiries, State insurance director. 5/26: mk s/w Carol Nightingale: obtained info fr her to follow up on. Ins co is to render appeal decision 6/15. She hasn't been able to locate appr ltr. Also, conflict between ins language and info given by pres of co. re donor expenses. S/W Sharon Bolster, RN w/ BMT program: gave additional info & referred me to Jennifer Hurley, coordinator in admissions. lmsg on v mail 4 c/b; need copy of apr ltr & info, if any re: donor expenses. S/W Jeff, pt's dad, & explained PAF info, snt pkt. he is to sign release form & mail back. Still needs assistance & is grateful for anything we can do.

07/16/98 15:05

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PATIENT ADVOCATE

National Managed Care Referrals

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
36 Blood & Marrow Trans. Newsletter	Sewickley	PA	U.S. Air	Health American Plan- Erisa	Breast Cancer--Mets to Bones	Dr. Boozer at MD Anderson recommends Homium 166 to reduce bone tumors fo patient can have BMT. Ins. will pay for BMT, but not Homium- Phase 1. Experimental	Resolved. (4-15-98) Spoke with Dr. Boozer, BMT Physician states durg is being provided at no additional charge to patient by pharmecudical co. Deborah Geisler states patient is good to go! She is interested in PAF info. Mailed packed to her.
37 BMT Newsletter	Swanton	VT	INS	MVP of VT	Breast Cancer to lung & liver	Pt need BMT. Insurer will not allow consultation; experimental; not viable candidate.	Resolved 3-18-98. Insurer approved initial induction of chemotherapy. With favorable response, insurer will reevaluate for transplant coverage.
38 Cancercare	Madison	NJ	Chatham Schools	BCBS-ERISA	Hodgkins Disease	Insurance won't cover sperm banking	Resolved. PAF ref pt to Planned Parenthood
39 Cancer Society	E. Green Bush	NY	Retired from railroad	United Health Care	Prostate Cancer	Wants to know if Medicare pays for prescryption drugs	Resolved. PAF advised pt that Medicare does not pay for prescription drugs. Since pt had already submitted appl. to pharm co for assistance, no further PAF act unless pt has problem.
40 Helping Hand Resource Guide	Jersey City	NJ	Social Wkr @ Christ Hosp.	not applicable		she wks in dept of radiation/oncology & has two patients who need help	mailed her pkt. She will be in touch w/ pts and have them contact me if they are interested in our help.
41 Aplastic Anemia Society	Irvine	CA	Retired.	Medicare	Myelodisplastic Syndrome	Pt needs assistance in paying for medicine.	Resolved. PAF contacted pharm co, Amgen. Amgen will pay if drug administered in dr ofc. Also, made pt aware of Safety Net Prog.
42 American Cancer Society	Newbergh	NY	Temple Hill School Cafeteria. Not working at present time.	New York Medicaid	Breast Cancer	Medicaid turned down because pt has name on mother's assets.	PAF advised to get her name off acct. File application with Medicaid.

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PATIENT ADVOCATE

National Managed Care Referrals

	C	D	E	F	G	H	I	J
	Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
43	ACS, Debbie Morganti	Jamestown	NY	Housewife	No Insurance	Breast Cancer	Pt has no insurance money to pay for doctor and radiologists fees. Medicaid was denied.	Called 4-7-98 and lines were busy. Marsha will check with pharm. co. for possibility of free meds.
44	ACS: Kathy Robbins	Waverly	NY	Unemployed	Uninsured	Lymphoma w/ mets to bone	Debt crisis intervention	Burr & Reed Collection Agency is handling her case
45	Friend	Ruidoso	NM	Self-employed- Real estate; c-21	Republic American Life	Breast Cancer- Stage 3	Insurance does not pay outpatient costs of treatment. Will not pay unless she stays overnight. Paid \$8000 cash- negotiated bills. Is there any recourse?	Christine Frisbee spoke with patient. Patient said she helped a lot. She directed the m to State Insurance Commissioner. (4-8-98) Left message at C-21 for return call.
46	BMT Newsletter	Clinton Township	MI	unemployed; husband retired	pt & husband on Cobra	Myelodysplastic Syndrome	Wants to reinstate under cobra; runs out in July	Cobra book was sent 3/20; need to follow up w/ pt
47	LSA	Jasper	AL	unemployed	Medicaid only pays 16 days	Hodgkins DZ	Debt crisis intervention	i. msg for Pearlene to c/b asap; need to fu w/ note
48	Barbara Shalala (DOL)	Orland	ME	Champion Paper	PCN HMO	Renal Transplant	drug coverage	
49	Leukemia Society	Boca Raton	FL	Independent/ Engineer	BCBS; he is uninsured now and has been.	acute mylegenic leukemia	1996-turned down by BCBS. 1. Legally-was that right? 2. Can be reinstated?	(3-23-98)Patient faxed letter of denial from BCBS. (4-8-98) Marsha left message for patient.

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PATIENT ADVOCATE

National Managed Care Referrals

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1 Guide	Lovington	NM	None. Contract ran out at Good Samaritan Home	National Rural Electric	Breast Cancer	Pt wants insurance to pay for credit card payments. Has doctor, hospital, credit card bills. (Pt paid for 2-week stay in motel in Houston for treatment.)	Contacted Sheldon Weinhaus. Debt Crisis Intervention planned. Left message for patient and suggested she call United Way financial crisis counseling. (4-16-98) left message for patient to check status of case. MK: 4/8 I msg on ans/ph 4/ c/b today or Tues; 4/21 pt called: she hasn't done anything for herself. Stated she had tried to call the un way sev times ut no/ans. I called infor for her area code: Obtained Cons Credit Counseling ph # and obt ger admin ofc #. S.w Betty who refered to Indigent Assistance, Delma Madrid (Administrator, her ofc stated she will be avail tomorrow. tried to contact pt sev time/lines busy. 4/21 unable to s/w pt; I msg on ans mach & included infor 4 her. Req that she as ms madrid about fin counseling. also, her phy could determine her dt of disability/ need to follow up w/ pt
50 ACS: Wendy	Chesapeake	VA	unemployed	Prudential		James wants ins for wife; his cobra expires and ins co's quote high rates	4/8: Spoke w/ James and made several suggestions. He obtained ins from Co. nx door. Resolved 4/15
151 unk	Saugerties	NY	unemployed	Empire Blue Choice	Synovial Sarcoma	pt needs chest x-ray, ins states she needs referral	mk referred her back to her primary care physician for referral. She participated in a study w/ NIH and the x-ray is a follow up for that. Suggested she contact NIH as well to see if they will pay for it if she can't get the referral. S/W pt. Still hasn't had x-ray. States NIH clinic is only open on Fridays from 1:00 to 4:00 and she has had a hard time getting up w/ them. I called her phy ofc and got fx # for her. She is to let me know the # for NIH (Pending)
152 ACS: Christina	Cairo	NY	Unemployed	Medicaid	Scitzo Hormonal Tumor: Breast Ca	Nds \$ 4 bills, rnt, food, etc. ins covered med bills	Resolved: 04/23, mld pkt, sheet "Fin. Resources 4 Ca Surv"; info 4 internet re resources in ones own community; ref her to ck churches w/ food pantry; clothes closet
153							

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PATIENT ADVOCATE

027

National Managed Care Referrals

	C	D	E	F	G	H	I	J
	Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1	Internet	Thousand Oaks	CA	Boeing Airlines	none given	heart condition	needs advisement re: non-payment of pre-approved medical services for By-pass. He has approval letter.	(4-13-98)Received package of info. from patient. Per N D-E, unable to assist pt since not ca-related. Pt has heart condition. (file-closed) <b>Resolved</b>
54	unk	Independence	OH	Retired	Medicare	Prostate Cancer	needs cryoablation surgery; Medicare will not pay	pt l.msg 4/22, mk s/w wife who knew nothing and refused to speak about him. Stated she would let him know I ret'd his call. 5/18 l. msg on ans machine for pt to call 800# and let me know if he still needed assistance. Also, sent pkt w/ note.5/20:mk s/w pt. he pd \$5K down for out-pt surgery. <b>(Pending)</b>
55	ACS	Deming	NM	None. Quit due to illness.	None	Chronic Myclogenous Leukemia	Needs BMT- he is on interfereron twice daily costs him \$400/week. Needs money for meds, doctor bills, or BMT.	4/15/98 wkd w/ Fran; contacted NM ins comm. Who directed to Med Assis Div, Indigent Fund. L. msg w/ Elizabeth Bradly (505)882277-3100. MK suggessted fund raising:OTF. Need to contact drug co:Hoffman-Larroche. 4/16 s/w Mary Kay Peraes @ med Assist &obtained indigent info to pass on to pt. No ans from pt. 4/22 no ans/or ans mach @ sis home;mld pkt w/ note re:pharm co. 5/18:no ans @ sis home #. <b>(Pending)</b>
156	National Cancer Society			None	none	MDS-pre-leukemia	Trying to get SS disability. Has been denied	She is meeting with a local lawyer that she retained. This case is closed unless she needs further assistance.5/19 MK tried to contact pt by phone, no answer/no ans machine. No address to send note/pkt. No ans @.# given for Attorney, Carl Miller. <b>(Pending)</b>
157	Judy Cowans-friend of Ann Lord	Lewstion	NY	none given	Community Blue	Brain tumor-Oligodenerog linoma	Wants information on herbal remedies, etc..	
158	Nat'l Cervical Ca Foundation: Carol Armenti	Lakewood	OH	unemployed	Cobra	Cervical Ca Stage IV w/ mets to bone	pt intrested in mallpractice	Explained that we get involed w/ ins pbims, job disc, and debt crisis intervention, not malpractice.(file closed) <b>Resolved</b>
159								

National Managed Care Referrals

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1 Chemo Care: Sarah	North Miami	FL		Medicaid: AFDC	Br Ca Stage II on Adria/Cytox & Taxotere	Needs help w/ telephone. She has spoken w/ ph co and when her past due bill is pd she will have to make a dep of approx 60 to 70\$.guessing. Owes \$315.00	no family support but has contacted St Atty ofc who is trying to obtain child support for her son. Has contacted ACS, Salv. Army; Quality of Care, and Bell South. Atty w/ State Chantale Suttle. Cath Ch helping w/ power & water. Mailed all info on resources available. Will follow up w/ her re: phone. <b>(Pending)</b>
80 Unk		FL				Ms. Bolint called for friend re: job discrimination	<b>Resolved:</b> 04/16; Bolint stated pt had already obtained local atty
61 ACS: Middleton, NY	Goshen	NY	Consultant 4 Port Authority of NY	Phy Health Services	Prostate Cancer	4/15/98:per pt, needs help w/ life ins. Is 5 yrs out ca free and has ltr fr phy. However, he has been denied coverage from a number of co's. he is to c/b when he hears from Prudential. 5/18:pt fx'd denial ltr. 6/12:pt s/w Derry but hasn't heard more fr him. Derry wat 2 snd pkt of info. 6/15: pt called, rec'd denial fr NY Life.mk s/w Derry. He rec'd info fr NY the other day & had dictated ltr 2 pt., pkt to go out soon. mk l msg. 4 pt to updt on ph @ wk. <b>Pending:fu sch 4: 6/18</b>	5/18:mk s/w Derry Haywood, he made a p/c to an underwriter, states pt s/b able to get ins. W/ no pbIm. L. msg 4 pt 2 c/b. 5/28 s/w pt's wife, still hasn't heard fr NY Life. No ins yet. 6/12: pt s/w Derry, but hasn't heard fr him yt. He is 2 snt pkt. 6/15:mk s/w Derry, states just rec'd info fr NY (application, etc) & had just dictated ltr to pt this am. Pkt 2/b mld asap. mk l msg on ph @ wk, 2 updt conversation w/ Derry. Pt c/b w/ much gratitude. <b>Pending:sch 4 fu 6/17</b>
62							

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15:10

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PATIENT ADVOCATE

029

National Managed Care Referrals

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1 Coping Magazine	Lincoln	NE	Joe Christensen, Inc.	U.S. Life	Cervical Cancer, Stage 2B	Insurance coverage when changing from one policy to another; re: pre-existing condition and waiting periods.	(4-6-98) Patient to contact US Life and former employer in Florida to check coverage. She will call back with info and we will reevaluate need at that time. S/W pt. States she is trying to look for a large company to work for. I gave her the information re: 'guarantee issue policy' and the shoppers guide for ca pts. She then told me about giving a deposition for the EEOC but that it had been over a yr since she has heard from them. She is going to try to obtain a copy of the tape or the info on the tape and get it to me. I will send her a pkt rx wk. 5/28 Pending)
63 ACS:NY				BCBS:WNY	CML	Nancy Bovey called; hosp told bro-in-law wld need 29K for donor chgs	<b>Resolved:</b> 04/23; hosp c/b stated chgs had been taken care of; wanted 2 know if further pblms could we help; discussed pre-d & pre-cert process. Alerted to log conversations; to req a copy of the apr ltr. She req PAF info; snt pkt.
64 Sister has ca, too. Gave pt # to call.	Eden	NC	none given	Medicare	Breast cancer w/lymph node involvement	Needs help with medical bills. Bills are \$2100 per treatment; she has had 2.	(4-15-98) Patient is to check with physician to see if he accepts XMDR. If so, she shouldn't have a balance to pay other than her deductible. She is ckg on Medicaid as well. 5/18 s/w pt. She rec'd pkt and obtained info which has helped. She has applied for retro-Medicaid back to March. <b>Resolved</b> 5/18/98
65 Wife had resource list @ wk but couldn't remember where she obtained info	Lafayette	IN	Liberty Mutual	n/a	lymphoma phy considers pt cured	husband has been in remission more than 5 yrs and needs LIFE ins. Rates too high.	I. msg for Becky to c/b asap need add'l info; s/w Becky @ wk, states they just rec'd denial from Dave's employer, Liberty Mutual. She is onc rn and felt that she & husband knew more about his dz than they did or were willing to acknowledge. Stated ok to speak w/ Derry and I'd be back in touch. Snt pkt, she will return consent form by fax. <b>(Pending)</b>
66							

07/16/98 15:11

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PATIENT ADVOCATE

National Managed Care Referrals

	C	D	E	F	G	H	I	J
	Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1	ACS	Rochester	NY	Sears	has applied for Medicaid	Neck/Throat/Head-cancer	Needs help getting immediate treatment and/or insurance coverage. No treatment is being provided due to lack of funds.	(4/16/98)Gave family member name and numbers of dental clinics in area. Suggested contact be made with billing dept. at hosp. to research "charity care" type funds. Advised that patient apply for medicare. 5/18 I msg on aris mach for updt asap to see if pt needed further assistance from us. 5/19: s/w Christen Kingsley (pt's significant other) states pt was able to have teeth extracted and has been recvg radiation 2Xwk. It is extremely difficult for pt to talk because of dz so Christen is having to handle all communication. They are having difficulty commun. w/ phy. She seems to be in a hurry, standing @ door ready to leave. Christen is so frustrated because she senses phy doesn't want to take time to explain 'things' to her. I suggested that she write down ?'s, take a tape recorder and explain to phy that they are under so much stress that she has a hard time understanding and remembering, to plz explain slowly and in 'layman's terms' what is going on. If she is not able to overcome this situation, I offered to call the phy to see if I could help. She will let me know h
67	ACS: Sherman Oak ofc: Vanise Blvd	Vannuy's	CA	unemployed	No Insurance	Ovarian	Jenny, pt's daughter, called for ins info	s/w daughter 4/24; gave state ins comm. Name & ph#'s. 5/26: Jenny states have spoken w/ st ins comm. & are in process of completing forms to apply for state ins pool. She is also to contact ins co's from ph book and ask about a 'guarentee issue policy' ( <b>Resolved</b> )
68	Brenda walker @Cancer Care Inc.	Toms River	NJ	none given	none	lung cancer	No insurance. Needs urgent chemotherapy and radiation	Marsha attempted to contact, unable to reach as of 4-16-98.
69								

07/16/98 15:12

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PATIENT ADVOCATE

031

National Managed Care Referrals

07/16/98

15:13

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PATIENT ADVOCATE

032

	C	D	E	F	G	H	I	J
	Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1	Cancercare	Louisville	KY	Nurse-not employed for past year	Anthem of Kentucky	ovarian cancer	Has been accepted to clinical trials of Phase 3 vaccine at Sloan-Kettering beginning May 4. Insurance denied coverage b/c it is out of network and "research".	(4-16) Requested copy of plan language, letters of denial and request.
70								
	Sentara Norfolk General	Virginia Beach	VA	none given	none given	Breast cancer w/ mets to lung and brain	Ref: Annie Duncan (Norfolk Gen) 4 assist. Low income/good fam w/ children.	(4-16-98) Mld pkt 2 Annie & 2 pt. Incl intro. note w/ inst 2 call MK 5/18 l.msg for Annie Duncan and Pt to c/b asap.
71	Leukemia Society of NY	Statten Island	NY	Manhattan Electric	Oxford Health Plan	Lymphoma	Pt concerned re: low payment fr ins co; to send copies of bills and ref. Ltrs fr phy; made \$2k deposit upon admission in Feb, 98	MK rec'd info 4/28, s/w Andrea Combs @ Ox. Hlth. States pt was approved for treatment @ Sloan Kettering but ins paying @ out of ntwk rts: pt responsible 4 ded & co-ins: \$2500.00 plus diff in ucr. Pt 2 c/b after allowing payment to settle out. Andrea stated bills were being pd @ 100% @ this time. Explained to pt so he could understand. <b>Resolved 04/28/98</b>
72	unsure		KS			leukemia	Had two transplants and had reached million dollar life time maximum.	(4-15-98) Issue was resolved by patient.
73								

National Managed Care Referrals

07/16/98 15:13 757 873 8999 PATIENT ADVOCATE 033

	C	D	E	F	G	H	I	J
	Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1	BMT Newsletter Susan Stewart	Henderson	NE	Private Practice	Nevada Care POS	AML	Pt's mom called, states donor search not covered	Eva Gerson to send copy of pol lang re trn cov; in reading ov phone, noticed cap of \$150k for allo trn; s/w Alana Hawkins @ F Hutchinson Ca Crt re Cap; states they don't do anything w/ ins until have donor. Pt willing to pay for search. MK contacted ins co to verify benefits. There is a \$500.00 ded then the benefits are pd @60% UCR, never goes into 100%. Itmx is 1 mil. if he goes out of netwk for transplant. If he goes to ntwk hosp, benefits would be 100%. Called Alana, she will get back w/ me. <b>(Pending)</b>
74	NCI	Randolf	MA	Bank of Boston; Sr accts mgr		Br Ca	Job Discrimination	4/13 ret ph/c to sis, no ans. 4/15: 4/15: mk l msg 4 c/b re sis pblms @ wk. Per Fran, hasn't c/b 4/16. 5/18/98 finally s/w pt's sis, Sandra Grace: called concerned about harrasment on the job. She will speak w/ her and have her call. Snt pkt to pt & info to sister. (5/18/98) Haven't heard back, so I l. msg on ans machine that if Andrea needed assistance that I'd be glad to help. Otherwise I need to close the file. 5/28/98 no response: resolved
75	ACS, Sherman Oak OFC							
76	ACS: California (818-905-7766)	Midson Hills	CA	unemployed	Medical(Gov't Ins) Champus eff 5/1/98	Brain Cancer	husband has just left her because he couldn't handle her ca. She has boy & girl, 1 & 2 yr old	Pt wants better physician choice but she was crying so much because of her husband and the situation he has left her in that I couldn't understand her. She is to call back when she can calm down some. I was very sympathetic towards her. <b>Resolved: 5/18/97</b> Champus now effective.
7								

National Managed Care Referrals

07/16/98 15:14 757 873 8999

PATIENT ADVOCATE

034

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1 Soc wkr @ Iowa Meth Hosp where pt orig-rec't tx	Santa Barbara	CA	Construction worker	BCBS of CA prudent buyer level III plan	non-Hodgkins lymphoma	pt 9 yrs out dz free needs better cov; must wait 10 yrs for regular cov w/ BCBS CA	pt's mom: Emily Camp called: pt on wtg lst for st of ca major risk pool. Ins premium now \$305 per mo, cymx \$50K, ltmx \$500K, not student, had BCBS LA w/ low prem, but when pt moved wouldn't cov in another state. Had cobra prior to that and since prem was lower they changed. to convert was too exp. snt pkt to pt and add'l info to mom, also ref to St Ins Com for CA, ok to ck w/ Derry to see if he can locate hlth and poss life ins co who would consider pt
38 Internet	Spokane	WA			Progressive Infantile Idiopathic Scoliosis		Father snt req by email; fu w/ ph call. S/w Sheldon Wienhouser, states since pt has Medicaid for now, he doesn't advise getting involved because dad feels there is Medicaid fraud, etc. If they have pblms during the transition period getting her on fathers new insurance, then we can discuss the situation @ that time. Anything can take place during the period of a yr. Mhk s/w Nd-e regarding situation. Updated parent. <b>Resolved</b> 5/20
need	Athens	NY	disabled	Capitol District Physicans Health Plan; Medicare eff 4/1/98	non-Hodgkin's Lymphomaa	Debt crisis intervention; ins was pre-x until 4/1/98	pt called 5/12/98: Discussed fund raising, info in pkt, consent form to be completed & returned. Req'd concise info re: past & present bills & how handled. She has contacted the ca ctr for financial assistance. Previous bills have been written off or greatly discounted. She is hoping 4 discount, knows bills will not be written off. Discussed medicaid and property. Pt owes approx 20K in bills to clinic and approx 4500 to clinic for scans, etc.
		IN				Ins pblml	call came in @ 2:52 on 5/15, mhk needs to r/call

National Managed Care Referrals

07/16/98 15:15  
 757 873 8999  
 PATIENT ADVOCATE  
 039

C	D	E	F	G	H	I	J
Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1							
21	Houston	TX				nds ins info	call came in @ 12:47 on 5/14, mhk needs to r/call
22		MI				ins pbml/lvg state, cobra?	call came in @ 10:50 on 5/15, mhk needs to r/call
	Tuscaloosa	AL	Stillman College professor	BCBS of Alabama	Breast Cancer	pt has been on fam leave of absence re: placement of her mom in rest home; she was dx w/br ca and is now considering leaving her job. Needs insurance clarification so she can continue her coverage.	pt called 5/26: mk to ck w/ present ins co re options for continuing w/ non-group plan. She doesn't want hr dept @ wk to know she is considering leaving @ this time. She is to research co's which provide "guarenteed issue policies" and contact ins commisioner for her state to obtain add'l info. snt pkt w/ cobra book.
23	Rochester	NY	Time Warner Communications	Preferred Care HMO	Breast Ca	Needs surgery to correct scar tissue causing pain & bladder pblms. Pt of the process includes liposuction. Ins company has denied re: cosmetic and not needed	5/22: pt's mom called; daughter joined via 3 way. Pt to send copies of all documents sent & rec'd fr Preferred Care, plan language, her appeal ltr. She has been to grievance and denied again. Frustrated, she wants to prepare for second grievance appeal. mhk to discuss w/ nde
4	Washington	PA	Zumstein	United Health Care Ntwk	Br Ca:3 nodes of 15 +	Job Discrimination	18 yrs @ facility, uses universal precaution, is pt. Respiratory therapist in ER. White count is considered normal for normal activity but because of interaction w/ pt's she is constantly sick. Hosp will not allow her to wk in another area. States if an RN is sick they will place them anywhere doing anything. she is to document everything in concise list of interaction w/ phy, pt, and employer. has 18yrr history of excellent work until dx w/ ca. snt pkt w/ consent form.
5							

National Managed Care Referrals

07/16/98

15-16

757 873 8999

PATIENT ADVOCATE

036

	C	D	E	F	G	H	I	J
	Source	City	ST	Employer	Insurance	Type of Illness	Problem	Resolution
1		Gaston	WI	pt wks part time	No Insurance	Brease Cancer Stage II	can part time employer cut hrs &/or eliminate job all-together. Once ins policy has been purchased, can policy be upgraded or downgraded?	s/w pt and explained that part time employees have no rights unless they are w/kg enough hours to be elig for ins benefits. <b>(Resolved)</b>
78	BMT Newsletter Susan Stewart	Naperville	IL	Amy wks: AdvoCare	n/a	Breast Ca	pt having chemo agents: interferon & ara-c (cytarabine); 1st drug apr by FDA, 2nd drug apr only by compendia. Ins had denied the 2nd one. Do we have any Cal. Laws or any info regarding compendia?	mhk suggested she go to drug co & obtain free drugs for pt. Compendia is a regarded as a "pre-approval" to the FDA. <b>Resolved</b>
9	Dr. Javier Kane	San Antonio	TX	None-patient is 6 years old	Cigna	Myelodysplastic (pre-leukemia).	Son had BMT in 1995. Father applied for family coverage and was denied because of the BMT.	4/13 Parent referred me to Jeane Lair @ home ofc in Dallas. She will pull records, speak w/ Cigna & see if there is anything she can do... is to c/b tomorrow, miled pkt to J. Lair & Jose Marin, Sr.; 4/17 Father called to thank us for our help. Ms. Lair just called, co is offering family coverage for \$213.42 per mo. He was excited even tho his \$ is very los. hs is out on wkmn's comp. s/w him re: fund raising to pay ins. Mld sheeton fin. resources, etc. <b>Resolved 04/27/98</b>
3		Dorchester	MA	N/A	N/A		1) wanted foundation info 2) is there a law that req. BCBS to provide pol info to the policyholder?	4/29/98: pt called w/ ?'s: mhk ans ?'s & mld pkt 2 inc booklets & doc's pertinent 2 concerns. FU p/c 2 confirm his concerns were satisfied. Resolved

**The Cancer Wars at HMO's by Susan Brink**  
**U.S. News and World Report, February 5, 1996, pgs. 69-70**

**Special Procedures:**  
**Doris Dunckleberger, 53**

Doris Dunckleberger was diagnosed with metastatic breast cancer, and her doctors at Memorial Sloan-Kettering Cancer Center in New York advised her to undergo a bone marrow transplant and high-dose chemotherapy. Because of the cost, she decided to have the last-hope procedure only if her HMO, Empire Blue Cross and Blue Shield agreed to pay. The company initially refused, calling the plan experimental. When Doris and her husband, Jay, hired a lawyer, the HMO finally agreed to pay.

**Denial of Specialist:**  
**Carley Christie, 9**

Carley was diagnosed with a rare kidney cancer called Wilms' tumor. Her father, Harry Christie, wanted her to be treated by physicians who had extensive experience with her disease. When he found out the surgeon his HMO had suggested had never performed the required surgery on a child, Christie and his wife decided to go to a pediatric surgical oncologist experienced in treating Wilms' tumors. When the article was written, Carley was 12 years old and has no sign of the cancer. However, her parents' decision to bypass their HMO's recommendation led to a nearly yearlong battle that resulted in an arbitrator's ruling that the HMO pay all medical bills.

**Special Procedure:**  
**Name Withheld:**

Following a lumpectomy, a woman was referred to Larry White, director of education and research for radiation oncology at the Washington Hospital Center's cancer institute for radiation treatment. A standard round consisted of 33 treatments over six weeks. Her insurer refused payment and expected the cancer team to reverify treatment every three days.

**Emergency Care Under Managed Care: A Fatal Distraction? by Gregory L. Henry**  
**Health Systems Review, March/April 1996, pgs. 55-62**

**Emergency Room Pre-authorization:**  
**Name Withheld:**

A 46-year old woman was rushed by ambulance to the emergency department in full cardiac arrest. Her husband had called 911 after she collapsed while getting out of the car. Despite heroic attempts to revive her over a 30-minute period, the woman died. Some months later, the patient's family received a notice from her HMO denying the claim because the patient had not called for authorization prior to going to the emergency department.

**Emergency Room Pre-authorization:****Name Withheld:**

The wife of a physician called her husband from out of town complaining of symptoms that could have been meningitis, a condition that is fatal in less than 24 hours. He told his wife to go to the nearest emergency room, where she was diagnosed with dehydration. However, because her husband's concerns about meningitis were wrong; even though he was a physician, their HMO refused to pay for the emergency room charges.

**Denial of Emergency Care:****Name Withheld:**

An eight-year old girl was brought to the emergency department suffering from fever, headache, and weakness. The girl and her mother were staying in a nearby shelter and belonged to an HMO through Medicaid. Following contract rules, the emergency staff contacted the HMO, where a nurse was fielding calls. Without ever seeing the child, she denied emergency care with no further instructions. Fortunately, the doctor ignored the denial and examined the girl anyway. The girl was diagnosed with meningococcal meningitis, which is a potentially fatal illness and could have infected the entire shelter of women and children.

**Denial of Emergency Care:****Name Withheld:**

A man in Texas who belonged to a national HMO went to the emergency department with a severe headache. He has suffered from high blood pressure and his father had died of an aneurysm, so the emergency physician wanted to admit the patient, concerned that he was at risk for an impending stroke. Acting in accordance with the rules, the doctor contacted the HMO and was told to treat the man as an outpatient with medication and later follow-up. A few hours after leaving the emergency department, the patient suffered a stroke.

**Letters from the People, Editorial****St. Louis Post-Dispatch, April 4, 1996, pg. 6B****Emergency Room Pre-authorization:****Name Withheld:**

A woman had slipped getting out of her bathtub and was sick to her stomach with a potentially broken arm. Because they were not sure what to do, her mother and daughter took her to the emergency room for X-rays. The arm was not broken, and on Monday morning the woman called her doctor's office on the advice of her insurance person at work. When she returned home that evening, there was a message on her answering machine that her doctor would not authorize payment because he had not been called first.

**Husband Sues HIP in Death: says HMO's Rules Helped Kill Wife by Roni Rabin****Newsday, February 27, 1996, pg. A02**

**Incompetent Care and Denial of Specialist:  
Sabina Friedman, 46**

Sabina Freedman began to suffer from a variety of symptoms including lower back pain, night sweats, and a galloping heartbeat. When she consulted her HIP doctor in September, 1990, the physician said her symptoms were related to menopause and sent her to a psychiatrist. Friedman continued to complain about her symptoms for two years. In September, 1991, she passed blood in her urine, yet the HIP doctors prevaricated, delaying appointments with specialists, sending her to a hospital that knew nothing of her case and told her to go home, taking weeks to authorize crucial but expensive diagnostic procedures. By the time an outside surgeon she went to on her own removed Friedman's left kidney, along with a tumor the size of a grapefruit, the cancer had spread to her lymph nodes. She died in June, 1993, leaving four children, then aged 14 to 25. Friedman's husband, Nathan, is suing the two HIP doctors who treated her and also has named HIP, the Health Insurance Plan of Greater New York, as a defendant.

**Costly Savings: Downside of the new Health Care; For a Few patients, Reform May Carry a Chilling Price by David S. Hilzenrath  
Washington Post, Final Edition, Monday August 7, 1995, Section A pg. 1**

**Incompetent Care:  
Costella Prince Thompson, 53**

When Costella Prince Thompson went to a Group Health Association Inc. urgent care center on March 12, 1992, she was suffering from a sore throat and a cough along with diarrhea, chills, nausea, and vomiting after undergoing general anesthesia for arm surgery a little more than a week earlier. At the health maintenance organization, she was examined by a physician, who prescribed some medicine and sent her home with instructions to stay in bed for four days. A day later, she was dead. An autopsy revealed pneumonia and a punctured esophagus, an internal abscess that extended from the surrounding tissue to her lung, that the physician assistant had missed, apparent complications of her surgery. A District jury faulted the care Thompson received at GHA, but decided that the HMO was not to blame for her death.

**Incompetent Care and Denial of Specialist:  
Lilia M. Reyes**

Beginning in October, 1991, Reyes, a program manager for the U.S. Conference of Mayors and a mother of two, complained to GHA of abdominal pains, bowel irregularities and other problems. By early 1992, when blood was detected in her stool, she told her GHA doctor that she feared she had colon cancer, according to court records of a malpractice suit. A test called a sigmoidoscopy who have certainly detected the problem. Physician Karen Bledsoe, an employee of the HMO at the time, diagnosed Reyes' problem as irritable bowel syndrome. Bledsoe testified that, before she could refer a patient to a specialist for a sigmoidoscopy, she would have to submit a form for review by GHA's chairman of internal medicine. She said that

she was denied such requests in some other cases. Reyes' cancer was diagnosed in August 1992 when she underwent emergency surgery while on vacation in Florida. A tumor had blocked her colon. One of Reyes' experts testified last November that he would be surprised if she would be alive in a year.

**San Diego in Lead of HMO Revolution by Barbara Marsh  
The Los Angeles Times, August 31, 1995, Part A, pg. 14**

**Denial of Specialist:  
Dr. Bonnie Hough**

Bonnie Hough was injured in a light plane crash in 1979, and lacks feeling in the lower half of her body and requires a wheelchair. In 1989, while retraining for a specialty in psychiatry at UC San Diego's medical school, Hough made a routine visit to see her primary care physician through the university's Health Net health plan. Hough requested a referral to a specialist in rehabilitation medicine, figuring an expert would ensure she received the special preventative care that paraplegics require. Unfortunately, her physician denied the request for a referral. About a month later, Hough became ill and developed a pressure sore on her buttocks that opened and drained pus. This is something that a rehabilitation doctor would have checked for and taken care of. Still, her primary doctor refused to refer her to a rehab specialist. The sore grew, and eventually she needed surgery to have a portion of her buttocks removed. Afterward, she spent three months in a nursing home and was on round-the-clock nursing care for months after that. As a result, Hough was incapacitated for a year.

**Kuhl v. Lincoln National Health Plan of Kansas City, Inc. (8th Cir. 1993) 999 F. 2d 298**

**Denial of Specialist:  
Mr. Kuhl**

Mr. Kuhl had a heart attack. His doctor decided on June 20, 1989 that he required specialized heart surgery. Because the hospitals in his town did not have the necessary equipment for such surgery, the doctor arranged for the surgery to be performed in St. Louis at Barnes Hospital. When Barnes Hospital requested pre-certification for the surgery, the utilization review coordinator at Mr. Kuhl's HMO refused to pre-certify the surgery because the St. Louis hospital was outside the HMO service area. Accordingly, the surgery scheduled for July 6 was canceled. The HMO instead sent Mr. Kuhl to another Kansas City doctor on July 6 to determine whether the surgery could be performed in Kansas City. That doctor agreed with the first doctor that surgery should be performed at Barnes Hospital. By then, the surgery could not be scheduled until September.

When the doctor at Barnes Hospital examined Mr. Kuhl on September 2, Mr. Kuhl's heart had deteriorated so much that surgery was no longer a possibility. Instead, he needed a heart transplant. Although the HMO refused to pay for an evaluation for a heart transplant, Mr. Kuhl managed to be placed on the transplant waiting list at Barnes. Mr. Kuhl died waiting for a transplant.

The survivors of Mr. Kuhl have no damages remedy against the HMO under ERISA. Mr.

Kuhl's survivors state law causes of action were eliminated due to ERISA.



## HMO Lawsuits

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USA Today reported on two HMO lawsuits. One is a wife, mother and teacher from Elsinore, California, Christine deMeurers who had breast cancer. Her doctors approved Mrs. DeMeurers for a bone marrow transplant, but her HMO, Health Net, refused coverage because it considered the treatment, in her case, to be experimental. Even though UCLA paid for her treatment, Mrs. deMeurers died last March at age 35. Her husband sued Health Net.

An arbitration panel of three persons ruled in October that Health Net breached its contract in bad faith and intentionally inflicted emotional distress. The arbitrators wrote that HealthNet "crossed the line" in improperly seeking to influence doctors' medical judgment and awarded \$1.2 million in damages.

U.S.A. Today also reported that Joyce Ching, a wife and mother in Agoura, California, visited her primary care doctor, Elvin Gaines of Simi Valley, California, with complaints of abdominal pain and rectal bleeding. Ching and husband tried for almost three months to get a referral to a specialist, but it was denied. When she was finally referred to a specialist, she was diagnosed with colon cancer. Mrs. Ching died in April 1994 at age 34. After her death, her husband, Dave Ching sued Gaines, Dr. Daniel Engeberg and their medical group for malpractice. Mark Hiepler, Ching's lawyer, also alleged a breach of fiduciary duty, charging that the doctors were motivated financially to deny referrals because they were being paid a capitated fee of \$27.94 a month to treat Ching and would have to pay out of their pocket for costs exceeding that amount.

In November, a Ventura County (California) jury found Gaines and Engeberg negligent and awarded \$3 million in damages - reduced to about \$700,000 under a California law. Before closing arguments the judge threw out the part of the suit alleging that Gaines and Engeberg acted out of greed.

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# BIOGRAPHICAL SKETCH



**JOYCE CHING**

access to  
specialist



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Joyce Ching lived with her husband David and five-year-old son, Justin in Agoura, California.

In 1992, David switched jobs, and even though they were offered an array of plans from which to join, Joyce was able to convince him to enroll in an HMO for the reason that it would allow them to remain with Justin's pediatrician at a local clinic.

In the Summer of 1994, Joyce herself got sick. She began to suffer from severe abdominal pain and rectal bleeding. The pain was so excruciating that some days she couldn't even get out of bed to play with her son. She visited her HMO doctor -- and was refused

doctor?

a referral to a specialist. She was told that her symptoms could be alleviated by a change in diet. They weren't.

Fearing that her illness could hamper her chances of having a second child, Joyce continued to complain to her doctor that her pain was getting worse. For more than two months, her doctors told her to just give her diet time. Finally, after nearly three months and countless visits, she received a referral to a gastroenterologist. But it was too late. Joyce was in the final stages of colon cancer -- and nothing could be done. She was only 34 when she died.

But what is so shocking about this case is that her doctors never took the time to listen to her concerns. The HMO and the clinic had reached an agreement capping Joyce's monthly medical expenses at \$27.94. For treatments exceeding that amount, the clinic would have to pay out of their own pocket. According to ERISA, the Employee Retirement Income Security Act, which governs managed care plans, Joyce's doctors and HMO had done nothing wrong.

Her doctors never took her medical history, or knew that her father also died at a young age of colon cancer. Had her doctors not tried to treat her cheaply, but rather treated her properly, Joyce Ching may still be alive.

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medical malpractice?

NO SPECIALIST

... then died

# BIOGRAPHICAL SKETCH

☆☆ sufficient access to doctors.

## BUDDY KUHL



[Click here to read Senator Dorgan's \(D-ND\) floor statement](#)

→ there is a right that says in those in network don't

Mr. Buddy Kuhl suffered a major heart attack. His doctor decided that he required specialized heart surgery. Because the hospitals in his town did not have the necessary equipment for such surgery, the doctor arranged for the surgery to be performed in St. Louis. <sup>have sufficient</sup>

When the hospital requested precertification for the surgery, the utilization review coordinator at Mr. Kuhl's HMO refused to precertify the surgery, because the St. Louis hospital was outside the HMO service area. Accordingly, the scheduled surgery was canceled. The HMO instead sent Mr. Kuhl to another Kansas City doctor to determine whether the surgery could be performed at a local hospital. That doctor agreed with the first in that the surgery should be performed in St. Louis. Two weeks later, the HMO agreed to pay for surgery as originally decided. By then, the surgery could not be scheduled until several months later. <sup>exp doctors can go out</sup>

When the doctor in St. Louis examined Mr. Kuhl two months later, Mr. Kuhl's heart had deteriorated so much that surgery was no longer a possibility. Instead, it was discovered that he needed a heart transplant. Although the HMO refused to pay for an evaluation for a heart transplant, Mr. Kuhl managed to be placed on the transplant waiting list in St. Louis. <sup>of net</sup>

Mr. Kuhl died several months later, still waiting for a transplant. He was 45 years old. He was survived by Mary, his wife of twenty-five years, and two children.

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↑ ↑  
Pick do you have to get back.

needed heart transplant, didn't get it

# BIOGRAPHICAL SKETCH



## PAIGE LANCASTER



[Click here to read Senator Dorgan's \(D-ND\) floor statement](#)

do they incenti-  
vise them not  
to see  
neurologist?  
programs

In 1991, when Paige Lancaster was eleven years old, her mother took her to see their HMO pediatrician in Woodbridge, Virginia after Paige complained of nausea and severe, daily headaches on the right side of her head. For the next four years, Paige repeatedly sought medical treatment for her headaches from two other HMO pediatricians. They prescribed adult strength narcotics, but never once consulted with a neurologist nor recommended an MRI, CAT scan, EEG, or any other diagnostic test to assess Paige's condition. In 1996, the school psychologist, worried about Paige's deteriorating high school performance, that she wrote to Paige's doctors urging them to perform diagnostic tests to determine the cause of Paige's debilitating symptoms.

Four and a half years later, Paige's doctors finally ordered an EEG and MRI. The MRI revealed a massive right frontal tumor and cystic mass that had infiltrated over 40% of her brain. A week later, Paige underwent surgery to remove the tumor. However, the surgery was unsuccessful because of the tumor's size and maturity. Paige underwent a second and third surgery and radiation therapy, and is likely to require additional surgery and ongoing intensive care.

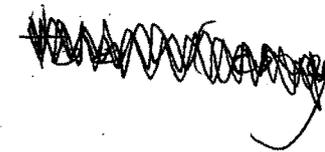
Throughout the nearly five-year period that the HMO pediatricians treated Paige, the HMO had in place a financial incentive program under which her physicians would receive bonuses for avoiding "excessive" treatments and tests.

The Lancasters turned to the courts to challenge the HMOs handling of Paige's case. Unfortunately for the Lancasters, insurance for their children was provided by Mr. Lancaster's employer, and is subject to federal Employee Retirement Income Security Act (ERISA) provisions. Under ERISA, the only available remedy to the patient is the cost of the benefit denied. The Lancaster could not recover anything for the pain and suffering, the costs of surgeries and hospital stays, and the loss of Paige's childhood -- only the costs of the delayed MRI and EEG tests.

The District Court had no choice but to turn away the Lancaster's claim of negligence against the HMO. Even though their practices have drastically changed the life of Paige Lancaster and her family for the worse, the HMO was let off-the-hook.

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refusal to consult  
specialist for 4 1/2  
years causing  
more surgery



Christa - this one could work  
bc of financial incentives  
if doctor was not referring  
possibly bc of that reason  
depends on if she specifically  
requested specialist -  
appeals?

### BIOGRAPHICAL SKETCH

**ETHAN BEDRICK**

*probably not*



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Ethan Bedrick was born on January 28, 1992. His delivery went badly, and as a result of asphyxiation, he has suffered from severe cerebral palsy and spastic quadriplegia, which impairs motor functions in all his limbs. Ethan was put on a regimen of intense physical, occupational and speech therapy to help him overcome some obstacles throughout his development.

At the age of 14 months, Ethan's insurance company abruptly cut off coverage for his speech therapy, and limited his physical therapy to only 15 sessions per year. This change was recommended by an insurance company doctor performing a "utilization review" of Ethan's case. The reviewing doctor cited a 50% chance that Ethan could walk by age 5 as a "minimal benefit" of further therapy. Further, the reviewing doctor never

met personally with Ethan, his family, or Ethan's team of regular physicians. Upon review, the insurer affirmed it position, with a second company doctor citing a single New England Journal of Medicine article on physical therapy and child development. The article was published in 1988 -- four years before Ethan was even born.

Further, the doctor also declared that prescribed therapeutic equipment, including a bath chair (designed for aiding his parents and care providers in his bathing) and an upright walker (to allow him upright movement and muscle development), were merely "convenience items," and costs not to be covered by insurance.

The Bedricks filed suit, and in 1996, the Fourth Circuit ruled the insurer's decision to restrict therapy was "arbitrary and capricious" because the opinions of their medical experts were unfounded and tainted by conflict. Further, the Court concluded that the neither the insurance plan nor corporate guidelines require "significant progress" as a precondition to providing medically necessary treatments.

The Court noted: "It is as important not to get worse as it is to get better. The implication that walking by age five...would not be 'significant progress' for this unfortunate child is simply revolting."

During the time of review and litigation, Ethan lost three years of vital therapy. And ERISA left the Bedricks with no remedy for compensation for Ethan's loss of therapy. The Bedricks' state law causes of action were eliminated due to ERISA.

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*X*

*no equip/PT*

**BIOGRAPHICAL SKETCH****JENNA JOHNSON**

no

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Jenna Johnson is a 15 year-old girl from Minnesota. Since birth, she has suffered from cerebral palsy, learning disabilities, and dystonia (a debilitating condition that affects muscle control). She is in need of constant care and monitoring, and intensive physical training.

Five years ago, her mother remarried, and Jenna was enrolled into her stepfather's HMO plan. However, Jenna was then under the care of 17 specialty doctors, most of whom were not in the plan's network. Additionally, Jenna's future care would now require referrals from a new pediatrician within the network -- one not familiar with Jenna's case. Realizing the mounting hassles of finding proper care, Jenna's mother and stepfather enrolled in a new HMO the next year, but with little success.

Once again, Jenna was placed in the hands of a previously unknown plan pediatrician. Although the need to once again switch therapists was cumbersome, the plan was able to provide Jenna and her parents with basic care. But the following year, the plan changed its rules, now requiring Jenna to receive referrals for all necessary services. More time was being spent battling the insurance company to speed approval for visits and medical apparatus than at doctor's appointments -- time that could have been better spent with the family. Once again, Jenna's parents decided to switch medical plans.

The Johnson's third HMO allowed Jenna to remain with the same team of doctors and physical therapists. However, the following year, trouble began anew.

In the Spring of 1996, Jenna's dystonia worsened. At the time she was taking 22 pills daily, and her weight had dropped to only 85 pounds. The medications induced dangerous side effects ranging from stomach damage to psychosis. The Johnsons found a pediatric surgeon in Pittsburgh who specialized in treating dystonia. To stem the side effects, he recommended surgically implanting an internal pump and catheter to deliver medication. However, the doctor was out of the region covered by the Johnson's HMO, and the request for the procedure was immediately denied. After an appeals process of more than 30 days, and countless visits to local doctors and letters to doctors in Pittsburgh and the HMO, the Johnson's plan allowed Jenna to undergo the procedure.

The cost to the HMO was no greater than if it had been performed in Minnesota. And Jenna's condition improved.

One year later, it was discovered the catheter had become disconnected, and would require another surgery, which was once again denied. Again, the Johnsons fought, and the request was approved only after doctors in Minnesota refused to operate. Shortly after the corrective operation, the Johnsons were dropped from their HMO.

The alternatives were plans the Johnsons had already tried and left. But they had no choice, and chose a plan despite being told outright that further treatment in Pittsburgh would be denied. They continually fear that coverage could again be denied if Jenna requires additional care.

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no Specialist

## BIOGRAPHICAL SKETCH

### GLENN NEALY



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In March of 1992, Glenn Nealy, a husband and father of two, was notified by his employer that he would be changing health plans. Glenn chose one after gaining assurances from its agents that the plan would enable him to continue treatment of his unstable angina from his regular cardiologist. Glenn was being treated for his ailment with a strict regimen including nitrates, calcium blockers and beta blockers.

On April 2, 1992, at the direction of the HMO, Glenn went to a plan-participating doctor for the purpose of gaining a referral for his treatment by his cardiologist. That doctor refused to see Glenn because he had not yet been issued his HMO membership card. The next day, Glenn returned with his enrollment form, but was again turned away. For three weeks, Glenn contacted his HMO about obtaining his card, and on two occasions was issued cards with incorrect and invalid information.

On April 9, the HMO doctor agreed to meet with Glenn. But he refused to give a referral, admitting that he didn't know the HMO's rules for allowing referrals. The doctor renewed Glenn's angina medication prescriptions, but they were left unfilled because the HMO provided Glenn's pharmacist with incorrect information. On April 29, the HMO informed Glenn that his requests for a referral were being denied because they had "a participating provider in the area." On May 15, having been continually denied authorization to see his trusted cardiologist, Glenn consented to seeing the plan's provider. The appointment was set for May 19. On May 18, Glenn suffered a major heart attack and died.

Since Glenn's insurance was provided by his employer, his family had no way to recover damages from the HMO. The HMO was governed by federal Employee Retirement Income Security Act regulations, which only allows a patient to recoup losses caused by the delay or denial of care. Since Glenn never incurred any medical expenses, his family was entitled, under the law, to nothing.

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*Handwritten scribbles*

*angina, couldn't get prescriptions filled, died*

### Senator Byron Dorgan's Managed Care Floor Speech

July 9, 1998

*\* - if this is a  
"no access to emerg.  
room when it where  
need  
arises  
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#### VAUGHN DASHIELL

Mr. DORGAN: Mr. President, our health care system is in a state of crisis -- a crisis of confidence. Many Americans no longer believe that their insurance companies can provide them with the access to care or quality of service they need.

Today I continue our series of stories describing how some managed care plans seem to have put cost saving before life-saving. The experience of Vaughn Dashiell is just one more example of the pressing need for Congress to act now to protect the rights of patients.

Vaughn Dashiell lived with his wife, Patricia, and their three children in Alexandria, Virginia. Vaughn owned and operated his own printing company.

On November 20, 1996, Vaughn stayed home sick from work suffering from a sore throat, dry mouth, and tunnel vision that limited his sight to 18 inches. He tried to get an appointment to see a doctor within his HMO network, but was told that none were available at his designated facility. Vaughn was able to speak only to the HMO-employed nurse on duty over the phone. She could have told Vaughn to go to an emergency room for treatment, but instead, told him to make a regular appointment although none were available.

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As Vaughn's symptoms worsened, he called his HMO again requesting permission to see a doctor somewhere, or to go to a nearby emergency room. Vaughn was told only to wait and that he would receive a call back from a doctor on duty. When the doctor on duty was consulted, he agreed that Vaughn should go to an emergency room, but neither made a call himself, nor followed-up to see that Vaughn was contacted. That night, Vaughn was not contacted, not by the nurse, the doctor, or any other HMO staff regarding his condition and requests for care.

The next morning, Patricia found Vaughn incoherent, with his "eyes rolling". She hurriedly called the HMO, hoping for an answer to Vaughn's problem. They advised her to call 911.

Vaughn arrived at the hospital at 9:18 am in a diabetic coma. His blood sugar level was more than twenty times greater than the normal level. Just over two hours after being rushed to the emergency room, Vaughn was dead from hyperglycemia. He was only 39 years old.

This should not happen in America. Health insurers should not be allowed to put profit before patients. Vaughn Dashiell's condition would have been treatable and curable if the health plan had enabled him to get the care he needed. But for an HMO driven by cutting costs, the needs of the patient did not come first. Had this HMO not placed their patients in the hands of a system weak in oversight and follow-up and instead allowed Mr. Dashiell the opportunity to see a doctor when he first felt threatened, he might still be alive today.

Mr. President, we must take up and pass meaningful patient protections this year. We have a bill, S. 1890, that would prevent tragedies like this from occurring. Under our plan, Vaughn would have had guaranteed access to needed care, especially in the case of an emergency. Under our bill, members of HMOs would be able to go to an emergency room without seeking their plan's approval if they felt their life was in danger.

This is only common sense. It should not be controversial. I will appeal once again to the Republican leaders of this body: Please bring our Patients' Bill of Rights to the floor for action. The President has promised to sign it into law. We are wasting valuable time.

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*no access to doctor*

The Patients' Bill of Rights provides these protections and more. The Senate should act on this bill as soon as possible. It has the strong support of more than 100 organizations, representing millions of patients, doctors, nurses, working families and consumers. Every day we delay, more tragedies like this take place. They shouldn't have to happen to any family, and they won't happen when this needed legislation is enacted into law.

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## BIOGRAPHICAL SKETCH

### PHYLLIS CANNON



[Click here to read Senator Dorgan's \(D-ND\) floor statement](#)

Phyllis Cannon was diagnosed with acute myeloblastic leukemia in September, 1991. She underwent a regimen of chemotherapy, which her HMO paid for, and her leukemia was beaten into remission. However, Phyllis' oncologist, fearful that the cancer could again surface, urged an analogous bone marrow transplant.

But Phyllis' HMO contended that procedure for first remission patients was still experimental. They refused requests to pay for the surgery, even though a bone marrow transplant procedure was covered under the terms of her plan.

Phyllis' oncologist fought vigorously for the procedure, supplying the HMO with the latest medical literature on the procedure, knowing that an urgent transplant was critical to Phyllis' health. Again the HMO denied coverage.

Phyllis, her husband, Jerry, and her doctor continued to fight. Finally, after a month, the HMO relented, and agreed to pay for the transplant. But they did not even notify Phyllis until a month later. It was too late. Phyllis' leukemia had returned. Phyllis died 6 weeks later.

Unfortunately, because Phyllis received her health coverage from her employer, her HMO was protected. Employer sponsored plans, like the one Phyllis had, are governed by the Employee Retirement Income Security Act (ERISA) which gives HMOs immunity from the harmful effects their decisions may incur. For Jerry Cannon, ERISA left him with no chance to hold the HMO accountable in any way for their decisions, which led to his wife's death.

Phyllis Cannon's story demonstrates the glaring need for patient protections including an end to the shield ERISA provides to health insurers and HMOs. Judge William G. Young, a Reagan appointed US District Judge, is clear to state where the problems lie, "ERISA has evolved into a shield of immunity that protects health insurers, utilization review providers, and other managed care entities from potential liability for the consequences of their wrongful denial of health benefits. ERISA thwarts the legitimate claims of the very people it was designed to protect."

Our system must do better. Americans deserve better care, and deserve the right to hold insurers accountable if they do not receive that care.

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no bone marrow t-plant

## BIOGRAPHICAL SKETCH

### KRISTIN BOLINGER



[Click here to read Senator Torricelli's \(D-NJ\) floor statement](#)

Kristin Bolinger is a 15 year-old girl from Spotswood, New Jersey. As an infant, Kristin developed unexplained, intractable seizures. The severity of the seizures has left her in need of specialized therapy and expensive diagnostic tests.

Five years ago, Kristin's parents enrolled in an HMO plan. Because of its rules, Kristin could no longer see the pediatricians and specialists that had treated her for her entire life. The HMO-prescribed pediatrician was unqualified to treat someone with Kristin's unique problems.

But the troubles are deeper than just that of doctor choice. The HMO has also left the Bolinger family in a desperate financial situation. It refuses to pay many of Kristin's medical bills -- deeming them "not medically necessary." In 1994, when the scoliosis caused by Kristin's condition required the use of a back brace, the HMO gave her an inferior one. A properly fitting, supportive brace was created only after an orthotist friend of the Bolinger's physician made one free-of-charge for Kristin.

Last August, Kristin underwent corrective spinal surgery for her scoliosis, and her physician prescribed home nursing care and physical therapy for her recovery. The Bolinger's HMO at first refused to pay for home nursing care. Fortunately, Kristin's mother, Cheryl, was able to reinstate the nursing coverage, but only after Kristin was left for one week with out necessary care. The HMO also ceased physical therapy after it was only half-completed, and again only after intervention by Kristin's parents and doctors was it reinstated -- albeit at an abbreviated schedule and with a two-week lapse in care.

Kristin's doctors are not satisfied with her post-operative rehabilitation. The essential question remains, how much additional damage has been done because of the HMOs unwillingness to pay for necessary treatments?

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HMO would not <sup>no</sup> → ok if we go to medical necessity.

no Back Brace

**QUOTES FROM CONSUMERS, DOCTORS, AND NURSES ON WHY THE  
REPUBLICAN LEADERSHIP PROPOSAL IS MORE RHETORIC THAN A  
PATIENTS' BILL OF RIGHTS**

**August 1, 1998**

“The Senate Republican Leadership bill fails to meet basic patient protections standards that the public demands.”

“We are concerned that S. 2330 would provide limited patient protections for only 48 million out of 161 million insured persons in this country. At this important crossroads, we cannot afford to leave some patient protections behind.”

**American Medical Association**

“The few consumer protections claimed for these alternative bills, S.2330 and H.R. 4250 are like the Wizard of Oz: if one looks behind the curtain there is pitifully little substance to be found.”

“For instance, the “so-called ‘independent medical review’ of decisions when the reviewer is allowed only to judge conformity with the plans definition of medical necessity is ‘a hoax.’”

**American Nurses Association**

“Beneath its rhetoric and mostly symbolic provisions, S.2330 clearly fails to address women’s well-founded concerns about managed care. It is cynical attempt to divert attention from the real issue: what kind of fundamental protections all Americans, and especially women, will really be able to count on in the era of managed care.”

“The Republican Leadership bill has many serious shortcomings. Most of its provisions do not even apply to about 100 million people ... it lets health plan bureaucrats, *not* doctors, have the last word in important treatment decisions ... it does *not* make sure that patients can see the specialists they need when they need to.”

**National Partnership for Women and Families**

“If this bill is enacted, it could be devastating for the thousands of women who undergo breast cancer treatment every year.”

“They don’t guarantee that breast cancer patients would have some fundamental rights, including: the right to receive accurate information about their health plans; access to the right providers; and involvement in treatment decisions based on good science. In short, these bills don’t provide women with what they need or what they deserve.”

“Continuity of care is another critical aspect not properly addressed in the Republican Patients’ Bill of Rights. Under this bill there isn’t adequate protection for a person whose employer changes to a plan that does not include the individual’s physician in its network. This is especially important for women dealing with complicated breast cancer procedures, chemotherapy treatments and ongoing care.”

#### **National Breast Cancer Coalition**

“The House and Senate GOP bills do little or nothing to improve the quality of care for small businesses and their workers. The House GOP bill shortchanges small businesses by excluding them from the grievances and appeals process, while almost none of the patient protections in the Senate bill apply to people with small business.”

#### **American Small Business Alliance**

“Unfortunately, the House and Senate Republican bill will not bring peace of mind to anyone seeking emergency care.”

“The Republican managed care bills will: lead to more coverage disputes not less; create confusion instead of clarity for patients and physicians; create new paperwork requirements for emergency room physicians; and establish new loopholes for HMOs to deny coverage for emergency services.”

#### **American College of Emergency Physicians**

### Senator Edward M. Kennedy's Patients' Bill of Rights Floor Speech

June 12, 1998

\* \* This could work as access to special  
out-of-pocket referral

#### JACK JENNINGS

Mr. KENNEDY. Mr. President, I am deeply concerned about the continuing lack of commitment by the Republican Leadership to schedule floor debate on legislation to end abuses by health insurance managed care plans. Today, more than 100 groups have sent a letter to Senator Lott and Speaker Gingrich asking for quick, full and fair floor consideration of this legislation, which is called the Patients' Bill of Rights. These groups represent millions of patients, doctors, nurses, therapists, and working families.

Yet, in a memo sent to all Senators and in recent floor statements, it appears that our patient protection legislation--the Patients' Bill of Rights--is not even on the Republican Leader's radar screen. It is not on the list of priorities designated by the Republican Leadership to be taken up this month, or even this session. I have here a list of more than 20 bills, ranging from regular appropriations bills and reauthorization bills to the nuclear waste disposal legislation and a constitutional amendment on flag burning.

But, I have yet to see any interest from the Republican Leadership in taking action to ensure that medical decisions are made by treating physicians, and not by insurance company accountants. And I have yet to see any interest from the Republican Leadership in curbing abusive activities by the worst plans and insurance companies that are dedicated to their profits, not their patients. Instead, it appears that, by this inaction, the Republican Leadership is interested only in defending the indefensible, the status quo.

In addition, the House Republican Leader, Dick Armev, recently lashed out at doctors, nurses and other health care professionals by grossly misinterpreting and distorting a provision in the Patients' Bill of Rights that allows health care professionals to support their patients in appeals procedures, and to report concerns about the quality of care without fear of retaliation. These are reasonable patient-oriented protections. Congressman Armev's misguided effort offends and impugns the character and professionalism of hundreds of thousands of nurses, doctors and patients.

In fact, his harsh attack has helped mobilize even more organizations to support the bill. Representatives Lois Capps, Carolyn McCarthy and Eddie Bernice Johnson, who are former nurses, and nurses from communities around the country have rallied around the Patients' Bill of Rights. Today, they have sent a letter to Congressman Armev asking for a meeting on these critically important issues. They are supported, in a separate letter, by a number of groups who represent persons with disabilities, mental illness and HIV/AIDS, and other organizations that rely regularly on trained and devoted health care professionals.

These issues matter a great deal to families across the country. Too often today, managed care is mismanaged care. In state after state across the country, patients are paying for these industry abuses with their lives.

Just ask Frances Jennings of Andover, Massachusetts. In November, 1992, at the age of 57, her husband Jack was diagnosed with mild emphysema by his pulmonologist. A few years later, in March, 1997, Mr. Jennings was hospitalized for a pneumothorax, which can lead to a collapsed lung. His physician, Dr. Newsome, determined that a lung reduction procedure would improve Jack's health and overall quality of life.

Two months later, in May, 1997, Jack's condition was stable enough for the operation, and he was referred to Dr. Sugerbaker, a top surgeon who specialized in the procedure.

But in late May, Jack's insurance plan--U.S. HealthCare--denied his referral to the specialist. Frances and Jack were disappointed that the plan refused to authorize the referral, and they requested a referral for consultation with a plan-approved physician. This appointment was finally scheduled for June 12.

But, on June 11, the new doctor's office called Jack to cancel his appointment, stating that the physician no longer accepted patients from the health plan.

Immediately following this cancellation, Jack's primary care physician--Dr. Newsome--contacted the health plan to obtain yet another referral. On June 18, a new appointment was confirmed for mid-July, four months after his initial hospitalization.

Tragically, Jack Jennings never had the opportunity to benefit from the procedure recommended by his doctor. Jack had been having trouble breathing, despite his continuous use of oxygen, and had been hospitalized at the end of June. During this hospitalization, they discovered a fast growing cancer in his chest. Lung surgery was out of the question, and it was too late for chemotherapy to be effective.

Mr. Jennings died on July 10--four days before his long-awaited appointment with the specialist. In fact, this appointment would have been with Dr. Sugarbaker's group, the same physician that U.S. Health Care had prevented Jack from seeing in May.

This is a clear case where needed health care was unnecessarily delayed, with tragic implications. Timely care could have saved Jack's life. The health plan's inability or unwillingness to provide it cost him his life.

Unfortunately, such abuses are far too common in managed care plans today. Congressional offices are flooded with letters and calls from constituents who need assistance. Newspapers tell story after story of the human costs of these abuses.

The Patients' Bill of Rights will help solve these problems, and restore confidence in the health care system. The Patients' Bill of Rights is a common sense solution. Nearly all of its provisions were recommended by the Presidential Advisory Commission on Quality in the Health Care Industry. Many are included in the voluntary code of conduct for members of the American Association of Health Plans, the managed care trade association. Some of the provisions are already being implemented for federal health programs, including Medicare. Still others are included in model laws written by the National Association of Insurance Commissioners. The Senate should act on this important legislation, and it should act now.

Mr. President, I ask unanimous consent that the letters I have mentioned may be printed in the Record.

There being no objection, the letters were ordered to be printed in the Record, as follows:

June 10, 1998.

Hon. Richard K. Arney,  
Majority Leader, House of Representatives,  
Washington, DC.

Dear Majority Leader Arney: As organizations representing health care consumers, we strongly support efforts to establish meaningful patient and quality protections. We believe that an essential component of that effort is to protect the rights of physicians, nurses and other health care professionals to speak out about quality concerns without fear of retribution. While the rise of managed care has created strong incentives to reduce costs and cut corners, many of those impacts are not evident to patients. Instead, patients need to rely on the ability of health care professionals to provide information and advocate on their behalf.

For that reason, we take strong exception to your May 15th 'Dear Colleague' expressing your opposition to H.R. 3605, the Patient's Bill of Rights. First, we do not believe that patients are served when those who care for them are gagged or handcuffed, unable to speak out because of contractual arrangements or the very real threat of retaliation. This is not just a question of being informed of all available and appropriate treatment options; it is also a question of knowing when patient safety is the risk because of quality problems.

Second, we strongly believe disagree with your contentions that nurses and doctors are only seeking financial gain and would use 'good faith' reporting protections 'to rationalize a financially motivated lie.' Nurses and doctors across this country have had the courage to challenge managed care and other health industry abuses, often at personal risk. Those abuses will not disappear if the health industry is allowed to continue using retaliatory threats to shield itself from investigation. If nurses, physicians and other health care professionals are afraid to speak out, quality concerns will go unreported and problems will be ignored. If this situation is allowed to continue, patients will be the real losers.

Our organizations understand that health care consumers benefit when workers have the ability to report poor quality, including medication errors, problems created by early discharges from hospitals, or fraud and abuse. We hope that you will come to realize the need for such patient protections and reverse your opposition, both to this provision and to the entire Patients' Bill of Rights. Patients know that nurses and doctors have been their advocates. It remains our hope that you and the Republican leadership will demonstrate that you also are advocates in the fight for quality care.

Sincerely,

AIDS Action Council; The Arc; Bazelon Center for Mental Health Law; Center on Disability and Health; Children and Adults with Attention Deficit Disorder (CHADD); Communications Workers of America; Consumer Federation of America; Consumers Union; Epilepsy Foundation of America; Families USA; Friends Committee on National Legislation; Gay Men's Health Crisis.

National Association of People with AIDS; National Association of Protection and Advocacy Systems; National Association of Social Workers; National Council of Senior Citizens; National Multiple Sclerosis Society; National Partnership for Women and Families; Neighbor to Neighbor; Older Women's League; San Francisco AIDS Foundation; Summit Health Coalition; United Cerebral Palsy Association; United Church of Christ, Office for Church in Society.

June 9, 1998.

Hon. Richard K. Arney,  
Majority Leader, House of Representatives,  
Washington, DC.

Dear Majority Leader Arney: On behalf of over 200,000 nurses, we would like to express our deep disappointment with Your May 15 'Dear Colleague' letter accusing nurses and other health care workers of being willing to lie about quality concerns in order to improve their financial status. Your letter demonstrates a profound lack of awareness of the integrity and concerns of nurses as well as the problems facing patients throughout this country.

The major impetus behind the patient protection bill is health care quality. An important part of that is providing patients with accurate information and ensuring that the health care professionals who treat them are able to meet their professional and ethical obligations to advocate on their behalf.

Every day, nurses are confronted with situations that place their patients in jeopardy. Insufficient numbers of nurses, the replacement of skilled nurses with untrained personnel, and incentives for early discharge are just a few of the problems. In some facilities, the growing crisis in quality has forced families to hire private duty nurses in order to ensure that their loved ones receive adequate care.

Nurses know about patient conditions and are justifiably alarmed. Yet, nurses who speak out risk termination, cutbacks in hours, and other forms of retaliation. The Patients' Bill of rights, H.R. 3605, seeks to protect nurses, doctors and other health care professionals who report quality problems to their employers, public entities and private accreditation organizations. It is an important first step in improving patient conditions.

Your opposition to even this limited provision is surprising and disturbing. Your statements that this provision is motivated by financial considerations is an insult to every nurse who struggles to provide the best possible care to her on his patients.

As Congress considers legislation to improve health care quality, we would like the opportunity to meet with you to discuss our views and describe the real world situation nurses see every day. We understand that your views as majority Leader are likely to reflect, or at least influence, those of the Republican leadership and the task force appointed by the speaker to make quality care recommendations. Therefore, we would appreciate meeting with those representatives as well. Please contact Cathy Hurwit at (202) 429-5006 if you have any questions or to arrange a meeting.

Sincerely,

Martha Baker, RN, President SEIU Local 1991, Miami, Florida, Candice Owley, RN, Wisconsin FNHP, President, FNHP Local 5001, Milwaukee, Wisconsin, Kathy Sackman, RN, President United Nurses' Association of California Pomona, California, Sandra Alexander, LVN, Vice President, AFSCME Local 839, Council 57, Daly City, California, Norma Amsterdam, RN, Executive Vice President Registered Nurse Division 1199NY/SEIU, New York, New York, David Bailey, LPN, Director AFSCME District #3, Mt. Vernon, Ohio, Sylvia Barial, RN, New Orleans Public Schools, School Nurse Chapter Chair, AFT Local 0527, New Orleans, Louisiana, Rowena Blackman-Stroud, NMS, SUNY-Brooklyn College of Medicine, Treasurer, AFT Local 2190, Brooklyn, New York, Glenda Canfield, RN, SETU Local 707, Santa Rosa, California.

Pia Davis, Vice President, SEIU Local 73, Chicago, Illinois, Carol Flynn, RN, Danbury FNHP, President, FNHP Local 5047, Danbury, Connecticut, Anne Goldman, RN, Federation of Nurses/UFT, Special Representative, AFT, Local 0002, New York, New York, Rhonda Goode, RN, SEIU Local 535, Pasadena, California, Pat Greenberg, RN, SEIU Local 200A, Fayetteville, New York, Jacqueline Himes, RN, Philadelphia Public Schools, Executive Board Member, AFT Local 00003, Philadelphia, Pennsylvania, Doris Lee, RN, AFSCME Local 152, Mililani, Hawaii, Bonnie Marpo, LPN, President, AFSCME Local 2245, Shippensburg, Pennsylvania, Linda McDonald, RN Rhode Island Hospital, President, FNHP Local 5098, Providence, Rhode Island.

Mary Lou Millar, RN, President, CHCA/NUHHCE, Wallingford, Connecticut, Carol Moore, LVN, AFSCME Local 1550, Houston, Texas, Sylvia Rawson, LPN, AFSCME Council 71, Sicklerville, New Jersey, Jan Salsich, RN, Westerly Hospital, President FNHP Local 5075, Westerly, Rhode Island, Katherine Schmidt, RN, Oregon FNHP, President, FNHP Local 5017, Portland, Oregon, Darla Shehy, RN, SEIU Local 1199P, Hummelstown, Pennsylvania, Diane Sosne, RN, President, SEIU Local 1199NW, Seattle, Washington, Al Thompson, RN, SEIU Local 660, Los Angeles, California, Ann Twomey, RN, Health Professionals and Allied Employees, President, HPAE/FNHP, Emerson, New Jersey, Nancy Yalanis, RN, CHCA/NUHHCE 1199, Southington, Connecticut.

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June 11, 1998.

Hon. Trent Lott,  
U.S. Senate, Washington, DC.

Dear Mr. Majority Leader:

The American people want and need the protection of Patients' Bill of Rights. As more and more families face unreasonable barriers to getting necessary health care approved from health maintenance organizations (HMOs) and other health insurance plans, it is clear that legislative action is needed. Public opinion surveys repeatedly show that the public's desire for managed care consumer protections is both wide and deep.

It is more than half a year since the President's Advisory Commission on Consumer Protection and

Quality in the Health Care Industry proposed, virtually unanimously, the adoption of a Bill of Rights. For many months it has been clear that strong support exists for the enactment of a genuine Patients' Bill of Rights. A number of bills including the Patients' Bill of Rights Act (S. 1890), the patients' Access to Responsible Care Act (S. 644) and others have such support and demonstrate that many members are in favor of bipartisan patient protection legislation.

It is therefore both troubling and puzzling that there has been a delay in consideration of this legislation. We believe that it is wrong to obstruct congressional consideration of genuine patient protection legislation. Your colleagues want such legislation. America's families need it. And it is a violation of fundamental fairness, and a disservice to families seeking health care, for you to block a vote on this important legislation.

We hope that you will lend your support to efforts to enact genuine managed care patient protection legislation--not a watered-down version and not one that is combined with 'poison pills.' We urge you to schedule quickly a full and fair debate on such legislation. Protecting America's families should be your number one priority. We urge you to act now.

Sincerely,

ACT UP Golden Gate, AIDS Action, AIDS Legal Referral Panel, AIDS Policy Center for Children, Youth and Families, AIDS Treatment News, Alzheimer's Association, American Academy of Child & Adolescent Psychiatry, American Academy of Neurology, American Academy of Physician Medicine and Rehabilitation, American Association for Marriage and Family Therapy, American Association for Psychosocial Rehabilitation, American Association for Respiratory Care, American Association of Children's Residential Centers, American Association of Pastoral Counselors, American Association of Private Practice Psychiatrists, American Association of University Women, American Association on Mental Retardation, American Board of Examiners in Clinical Social Work, American Cancer Society, American Chiropractic Association, American Counseling Association, American Dental Association, American Federation of Labor-Congress of Industrial Organizations (AFL-CIO).

American Federation of State, County and Municipal Employees (AFSCME), American Group Psychotherapy Association, American Lung Association, American Medical Association, American Medical Rehabilitation Providers Association, American Nurses Association, American Occupational Therapy Association, American Protestant Health Alliance, American Psychiatric Association, American Psychiatric Nurses Association, American Psychoanalytic Association, American Psychological Association, American Society for Adolescent Psychiatry, American Society of Plastic and Reconstructive Surgeons; American Speech-Language-Hearing Association; American Therapeutic Recreation Association; American Thoracic Society, Anxiety Disorders Association of America; Arc of the United States, Asian & Pacific Islander Wellness Center, Association for Ambulatory Behavioral Healthcare, Association for the Advancement of Psychology, Association of Women's Health, Obstetric and Neonatal Nurses.

Bazelon Center for Mental Health Law, Brain Injury Association Inc (BIA), Center for Patient Advocacy, Center on Disabilities and Health, Child Welfare League of America, Children and Adults with Attention Deficit Disorders (CHADD), Clinical Social Work Federation, Consumer Coalition for Quality Health Care, Consumer Federation of America, Corporation for the Advancement of Psychiatry, Families USA, Family Voices, Friends Committee on National Legislation (Quaker), Gay Men's Health Crisis, Health Initiatives for Youth, Human Rights Campaign, International Association of Psychological Rehabilitation Services, League of Women Voters of the United States, Legal Action Center, Lutheran Office for Governmental Affairs of the Evangelical Lutheran Church in America.

National Alliance for the Mentally Ill, National Association for Rural Mental Health, National Association for the Advancement of Orthotics and Prosthetics (NAAOP), National Association of Alcoholism and Drug Abuse Counselors, National Association of Developmental Disabilities Council, National Association of People with AIDS, National Association of Protection & Advocacy Systems, National Association of Psychiatric Treatment Centers for Children, National Association of School Psychologists, National Association of Social Workers, National Caucus and Center on Black Aged, Inc., National Citizens' Coalition for Nursing Home Reform, National Council for Community

Behavioral Health, National Council on Aging; National Easter Seal Society, National Education Association, National Marfan Foundation, National Mental Health Association, National Minority Aids Council, National Organization for Rare Disorders (NORD), National Organization on Disability, National Osteoporosis Foundation, National Parent Network on Disabilities, National Partnership for Women & Families, National Patient Advocate Foundation.

National Therapeutic Recreation Society, National Women's Law Center, Neighbor to Neighbor, OWL, Paralyzed Veterans of America, Project Inform, RESOLVE, The National Infertility Association, San Francisco AIDS Foundation, Service Employees International Union (SEIU), Summit Health Coalition, United Cerebral Palsy Association, United Church of Christ, Office of Church in Society, Women's AIDS Network. National Therapeutic Recreation Society, National Women's Law Center, Neighbor to Neighbor, OWL, Paralyzed Veterans of America, Project Inform, RESOLVE, The National Infertility Association, San Francisco AIDS Foundation, Service Employees International Union (SEIU), Summit Health Coalition, United Cerebral Palsy Association, United Church of Christ, Office of Church in Society, Women's AIDS Network.

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## Senator Byron Dorgan's Managed Care Floor Speech

July 7, 1998

\* \*

physicians

### JACQUELINE LEE

This could work - w/ emphasis

Mr. DORGAN: Mr. President, our health care system is in a state of crisis -- a crisis of confidence. Many Americans no longer believe that their insurance companies can provide them with the access to first care or quality of service they need.

half story

Today I continue our series of stories describing how some managed care plans seem to have put cost saving before life-saving. The experience of Jacqueline Lee is just one more example of the pressing need for Congress to act now to protect the rights of patients.

Jacqueline Lee lives in Bethesda, Maryland. A lover of the outdoors, she took a trip to hike in the Shenandoah Mountains in the summer of 1996. While walking on one of the trails, she lost her footing, and plummeted off of a 40-foot cliff to the ground below. Luckily for Jacqueline, she was quickly airlifted from the mountain to a hospital in Virginia. Amazingly, she survived the fall, sustaining fractures in her arms, pelvis, and her skull.

Incredibly, her HMO refused to pay the more than \$10,000 in hospital bills. They said Ms. Lee had failed to gain "pre-authorization" for her emergency room visit. To this insurer, the fact that she was unconscious was no exception. For over a year, she challenged her HMO and faced personal bankruptcy. Ultimately, the Maryland Insurance Administration ordered the insurer to pay the hospital and fined them as well for their initial refusal to cover Ms. Lee's medical expenses.

Yet her struggle wasn't over. Within a year, after follow-up surgery for her injuries, Ms. Lee found herself back in the emergency room, fearing that she was suffering complications from surgery. Not wanting to go through another ordeal, this time she called her HMO beforehand. They told her they would pay only for her screening fees because the visit was not considered "a medical emergency."

Mr. President, we must take up and pass meaningful patient protections this year. We have a bill, S. 1890, that would prevent situations like this from occurring. Under our bill, Jacqueline Lee would have access to emergency care without preauthorization, and when she feels her life in is danger -- not when the insurance company tells her it's okay. Under our bill, Jacqueline would have been covered for her injuries-- she would not have had the rug pulled out from under her by the HMO.

We have only a few weeks of legislative business left to act. Whatever we do will not alleviate the stress that Jacqueline Lee has endured, but we can ensure that others do not have to spend time fighting insurers that would be better spent fighting for their health. We must guarantee patients the peace of mind that comes with knowing that their health plan will be there to help them recuperate, not deny payment because it improves their bottom line.

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# BIOGRAPHICAL SKETCH

## WENDY CONNELLY



[Click here to read Senator Dorgan's \(D-ND\) floor statement](#)

*Handwritten notes:*  
→ This could  
be a  
too  
adverse  
not as  
as horrific  
as former

Wendy Connelly is a wife and mother from Sherwood, Oregon.

In 1994, while experiencing symptoms of what she feared was a heart attack, including heaviness in her chest and a heart-rate approaching 150 beats-per-minute, Wendy sought treatment at a local hospital emergency room. Luckily, the doctors on-call treated her for what was not a heart attack, but rather a previously undiagnosed thyroid imbalance.

When she first began to fear the worst, Wendy had contacted her HMO's on-call physician for advice. Obviously unable to make an over-the-phone diagnosis, he told her to seek emergency room care if she felt her symptoms were not subsiding.

When the bill came due, the HMO denied Wendy's claim, citing that her case was not deemed "emergent care." The HMO was basing its opinion on the final diagnosis, not the heart attack-like symptoms that sent her to the hospital.

Wendy was convinced the HMO was wrong in their denial. For more than a year, she sent letters explaining her situation. Even her doctors and the hospital that treated her urged the HMO to cover her claim. Finally, the HMO conceded, and Wendy was no longer liable for the costs she incurred more than a year before.

Wendy decided to help others that she felt were being unfairly denied their deserved coverage. She filed a complaint against her HMO with the Oregon Department of Insurance. It was found that this was routine practice for this insurer -- if a person goes to the emergency room, but the final diagnosis shows a non-emergent condition, the claim was denied.

Luckily for Wendy Connelly, she was not having a heart attack. But just because her final diagnosis was not life-threatening does not decrease the seriousness of her symptoms. People suffering the symptoms of what could be life-threatening illness should not have to second-guess themselves before going to the hospital. It is only a matter of time before someone with Wendy's symptoms does not go the hospital, for fear of having their claim denied, who actually is suffering a heart attack.

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