The Arthritis Research Center
National Data Bank for Rheumatic Disease

ARTHRITIS RESEARCH PROJECT- RA/FIB

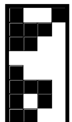
Phase 56

Date you completed this questionnaire:

__ __ / __ __ / __ __ __ __
(mm/dd/yyyy)

FOR OFFICE USE ONLY

1 0



42594

__ __ / __ __ / 2 0 0 9

20090101

January 2009

Welcome!

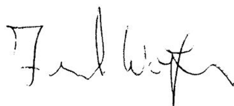
Whether you are new to our questionnaire, returning after some time away, or are one of our faithful experienced participants, we welcome you. If you have been helping us for some time we say thank you. We encourage you to read through the instructions below. They will help to make the time you spend filling out the questionnaire worthwhile for both you and us. You will need to complete EACH page of the survey so we can update existing information as well as get your new or current information.

Please note that most questions pertain to the time frame of July 1, 2008 to December 31, 2008, unless otherwise noted. Most of the questions you may have seen before. A few of the questions may seem to be very much alike, but they are all worded and scored differently. Because of this we do want you to answer each question, even if it seems similar to a previous question.

Each of you makes a valued contribution to this work. Sometimes people think that their disease is too mild, or too severe, or they aren't taking medication, or they have additional conditions not related to arthritis, so we might not want them to continue in the study. Nothing could be further from the truth. We need the experience of each of you to further refine and develop this data bank, which continues to be the largest and most comprehensive in the world. We appreciate each and every one of you!

As always, if you need help with your questionnaire, or have a question, call us at 1-800-323-5871 and then follow the instructions. You may also fill out the questionnaire online by going to www.arthritis-research.org.

Best wishes,



Fred Wolfe, MD

Instructions

1. You will need a blue or black pen that won't bleed through the paper. Please do not use pencil or red ink.

2. You will see a lot of small squares like this: ☐ Yes ☐ No

   These squares should be marked with an X like this: ☒ Yes ☐ No

   Be sure to make your X inside the box, and fairly heavy, so the computer can read it.

3. You will also see some boxes that look like this: ☐☐

   For optimum accuracy, please print carefully and avoid contact with the edges of the box. The following will serve as an example:

0	1	2	3	4	5	6	7	8	9

   Please--no fractions or decimals!!

4. If more space is needed for any question, please use the comment area on page 26.

5. You will also see some scales like the one below. You will need to make a mark in the box that best corresponds to your answer. These scales are usually 0-100. Read carefully to determine what the question is asking. In this example, the box marked with an X represents a person having a great deal of pain.

   0 ... **100**

   NO PAIN ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☒ ☐ ☐ SEVERE PAIN

BACKGROUND AND MEDICAL HISTORY

What is your **current** height and weight? (to the nearest inch or pound) Height ☐ Feet ☐☐ Inches Weight ☐☐☐ Pounds

If you are age 30 or older, approximately what was your height and weight at **age 30**? (to the nearest inch or pound) Height ☐ Feet ☐☐ Inches Weight ☐☐☐ Pounds

Current marital status? *(check one)*
☐ Never Married ☐ Separated ☐ Widowed ☐ Remarried after divorce
☐ Married ☐ Divorced ☐ Remarried after death of spouse ☐ Domestic partner

Do you smoke cigarettes? ☐ Never ☐ Now ☐ In the Past
If you smoked in the past or currently smoke: How many years? ☐☐ How many packs per day? ☐

Because of your health, how often do you depend on another person for help?
☐ None of the time ☐ A little of the time ☐ Some of the time ☐ Most of the time ☐ All of the time

Who is/are the persons on whom you depend for help? (mark all that apply)
☐ No one ☐ Grandchildren ☐ Professional aide ☐ Neighbors
☐ Husband/wife/partner ☐ Parents ☐ Home Health Nurse ☐ Friends
☐ Daughter/Son ☐ Other relatives ☐ Volunteer ☐ Other

Do you regularly drink alcoholic beverages? ☐ Never ☐ Occasionally ☐ Regularly
How many alcoholic drinks do you usually have in a typical day? If none, put 0 in box. ☐☐

Beer: 1 drink = 12 oz. can or bottle
Wine: 1 drink = 6 oz. glass
Hard liquor: 1 drink = 1 1/2 oz. liquor

CURRENT HEALTH PROBLEMS

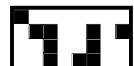
Please put an X in the first column if you have this problem now. If you have had the problem in the past, put an X in the second column.

Health Problem	I have had this in the last 6 months	I had this problem in the past	Health Problem	I have had this in the last 6 months	I had this problem in the past
High blood pressure	☐	☐	Cataract	☐	☐
Heart Attack	☐	☐	Asthma	☐	☐
Other heart condition	☐	☐	Severe allergies	☐	☐
Stroke	☐	☐	Liver problem	☐	☐
Depression	☐	☐	Gallbladder problem	☐	☐
Mental Illness	☐	☐	Ulcers	☐	☐
Diabetes	☐	☐	Other stomach problem	☐	☐
Cancer	☐	☐	Neurological problem (like seizures, Parkinson's disease, multiple sclerosis, etc.)	☐	☐
Alcohol or drug problem	☐	☐	Fractures of the spine/hip/leg	☐	☐
Kidney problem	☐	☐	Thyroid or endocrine disorder	☐	☐
Lung problem	☐	☐	Problems with prostate (men) Uterus, ovaries, etc. (women)	☐	☐

FOR WOMEN ONLY: REPRODUCTIVE HISTORY

1. Were you pregnant during the period **July 1 to December 31, 2008**? ☐ Yes ☐ No
2. How old were you when your menstrual periods started? ☐☐ Age in years
3. How old were you when your menstrual periods stopped? ☐☐ Age in years
4. Are you still having menstrual periods? ☐ Yes ☐ No
5. We are interested in the effects of arthritis in reproductive function. If you have ever been pregnant and are willing to be sent a questionnaire on arthritis and the effects in reproductive function, please check this box. ☐

9382



Participants in the NDB can have any rheumatic disorder, including Rheumatoid Arthritis, Osteoarthritis, Lupus, Scleroderma, Fibromyalgia, Ankylosing Spondylitis, and so on.
For most of these conditions we need to ask the same questions, so it doesn't make sense for us to create separate questionnaires for each disorder.
We use "Arthritis" as an umbrella term that really means any rheumatic disorder.

MEDICAL AND DIAGNOSTIC PROCEDURES

How many visits to doctors/other health workers did you have from July 1 and December 31, 2008? Do not include visits while you were in the hospital.

	1-2	3-4	5-6	7-8	>8
Rheumatologist	☐	☐	☐	☐	☐
Family physician, General Practitioner or Internist (Nurse practitioner/Physician assistant)	☐	☐	☐	☐	☐
Gastroenterologist (stomach or bowel specialist)	☐	☐	☐	☐	☐

	1-2	3-4	5-6	7-8	> 8
Chiropractor	☐	☐	☐	☐	☐
Physical or occupational therapist	☐	☐	☐	☐	☐
Other doctors (dermatologist, general surgeon, urologist, proctologist, cardiologist, orthopedic surgeon, podiatrist)	☐	☐	☐	☐	☐
Other health workers (social worker, psychologist)	☐	☐	☐	☐	☐

From July 1 and December 31, 2008 how many visits did you have to any of the following practitioners: Massage Therapist, Acupuncturist, Herbalist, Acupressurist, or Homeopathic practitioner?

☐ 0 ☐ 1-4 ☐ 5-8 ☐ 9-12 ☐ 13-16 ☐ 17-20 ☐ 21 or more

From which type of Doctor do you get most of your care for the following problems:

Arthritis or rheumatology problem

☐ Family physician or General Practitioner or Internist ☐ Rheumatologist ☐ Orthopedist ☐ Other Specialist ☐ None

General medical problem

☐ Family physician or General Practitioner or Internist ☐ Rheumatologist ☐ Orthopedist ☐ Other Specialist ☐ None

Osteoporosis

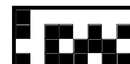
☐ Family physician or General Practitioner or Internist ☐ Rheumatologist ☐ Orthopedist ☐ Other Specialist ☐ None

How many diagnostic tests or treatments did you have in each of the following categories between July 1 and December 31, 2008? Do not include any that were done while you were an inpatient in the hospital.

	1	2	3	4	> 4
Xray of hand, wrist, foot or ankle	☐	☐	☐	☐	☐
Xray of shoulder, hip, or knee	☐	☐	☐	☐	☐
Xray of neck , spine, chest and lower abdomen	☐	☐	☐	☐	☐
Mammogram	☐	☐	☐	☐	☐
Nuclear Medicine Scans (For example, bone, lung, liver or heart scans)	☐	☐	☐	☐	☐
CT scan	☐	☐	☐	☐	☐
Endoscopy, gastroscopy (looking into stomach through a tube down the throat) If yes, please list on pg 9	☐	☐	☐	☐	☐
Esophageal dilatation (stretching the esophagus)	☐	☐	☐	☐	☐
Colonoscopy or sigmoidoscopy	☐	☐	☐	☐	☐

	1	2	3	4	> 4
Treadmill test	☐	☐	☐	☐	☐
Other Heart Tests	☐	☐	☐	☐	☐
Doppler exam	☐	☐	☐	☐	☐
Lung Tests	☐	☐	☐	☐	☐
Bone density test	☐	☐	☐	☐	☐
Sleep test	☐	☐	☐	☐	☐
Blood tests	☐	☐	☐	☐	☐
Urine tests	☐	☐	☐	☐	☐
Magnetic Resonance Imaging (MRI)	☐	☐	☐	☐	☐
Blood transfusion	☐	☐	☐	☐	☐

29869



MEDICAL CONDITIONS & HISTORY

The following questions ask about current medical conditions.

1. Do you currently have any of the following lung problems?

Emphysema	☐ Yes	☐ No
Asthma	☐ Yes	☐ No
Chronic bronchitis	☐ Yes	☐ No
Chronic obstructive pulmonary disease (COPD)	☐ Yes	☐ No
Pulmonary Hypertension	☐ Yes	☐ No

2. Please answer the following questions **whether or not** you have a lung problem:

I only get breathless with strenuous exercise.	☐ Yes	☐ No
I get short of breath when hurrying on a level or up a slight hill.	☐ Yes	☐ No
I walk slower than people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level.	☐ Yes	☐ No
I stop for breath after walking 100 yards or after a few minutes on the level.	☐ Yes	☐ No
I am too breathless to leave the house.	☐ Yes	☐ No

3. Do you **currently** take an aspirin or baby aspirin a day for your heart? ☐ Yes ☐ No

The following sections ask about medical conditions between July 1 and December 31, 2008.

Cancer

Between **July 1 and December 31, 2008** were you told that you had any kind of cancer or malignancy? ☐ Yes ☐ No

(Please list ALL of the types of cancer diagnosed between July and December on the lines below. For example: leukemia, lymphoma, lung, skin, breast, etc.)

1. ______________________ 2. ______________________ 3. ______________________

Lungs

Between **July 1 and December 31, 2008** were you treated for:

A pulmonary embolism or blood clot in your lungs?	☐ Yes	☐ No
Some other blood clot or DVT (deep vein thrombosis)?	☐ Yes	☐ No
Fluid around your lung (pleural effusion)?	☐ Yes	☐ No
Fibrosis of the lung?	☐ Yes	☐ No

Between **July 1 and December 31, 2008:**

Were you diagnosed for the FIRST TIME with Tuberculosis (TB):	☐ Yes	☐ No
Did you have a TB skin test in the last year?	☐ Yes	☐ No

Cardiovascular (Heart)

Between **July 1 and December 31, 2008** did you have or were you treated for :

Heart Failure	☐ Yes	☐ No
Heart Attack/ Myocardial Infarction (MI)	☐ Yes	☐ No
High Cholesterol	☐ Yes	☐ No
Stroke	☐ Yes	☐ No
High Blood Pressure	☐ Yes	☐ No

Between **July 1 and December 31, 2008**:

Did you notice any swelling (edema) of your body parts that was not due to arthritis?	☐ Yes	☐ No
Did you become aware of any increase in your blood pressure?	☐ Yes	☐ No
Did you have any problem controlling your high blood pressure?	☐ Yes	☐ No

18686

The following sections ask about medical conditions between July 1 and December 31, 2008.

Renal

Between **July 1 and December 31, 2008** did you have or were you treated for:

- Renal or Kidney Failure ☐ Yes ☐ No
- Reduced kidney function or high creatinine ☐ Yes ☐ No
- Did a doctor tell you that you had blood or protein in your urine? ☐ Yes ☐ No

Skin

Between **July 1 and December 31, 2008** did you have or were you treated for:

- Psoriasis ☐ Yes ☐ No
- Shingles (Herpes Zoster) ☐ Yes ☐ No
- Cold sore (Herpes Simplex) ☐ Yes ☐ No
- Human papillomavirus (Genital warts) ☐ Yes ☐ No

Liver

Between **July 1 and December 31, 2008** did you have or were you treated for:

- Liver problems ☐ Yes ☐ No

Stomach

Between **July 1 and December 31, 2008** did you have or were you treated for :

An ulcer (a stomach or duodenal ulcer)? ☐ Yes ☐ No

If yes, which of the following did your physician use to diagnose your ulcer? (Mark all that apply)

☐ X-ray ☐ Endoscopy ☐ Talking to you about your symptoms

Between **July 1 and December 31, 2008** did you have or were you treated for :

Helicobacter pylori or H. Pylori, a stomach bacteria? ☐ Yes ☐ No

Other Medical Problems

Between **July 1 and December 31, 2008** did you have or were you treated for :

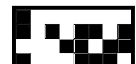
- Multiple Sclerosis (MS)? ☐ Yes ☐ No

  If you had Multiple Sclerosis (MS) **before July 1, 2008** did the problems get better, get worse or stay the same?

  ☐ Get Better ☐ Get Worse ☐ Stay the Same

- Systemic Lupus, Lupus or any other auto immune disorder? ☐ Yes ☐ No
  (e.g. Sjogren's, Crohn's Disease, Ulcerative Colitis, Guillain Barre, thyroid disorder, etc.)?
  This does NOT include RA.

  If yes, what was the diagnosis? ______________________



The following sections ask about medical conditions between July 1 and December 31, 2008.

INFECTIONS

Did you have any infections from **July 1 and December 31, 2008**? ☐ Yes ☐ No — If "yes" please answer section directly below.

Type of Infection - please place an X next to the type of infection that you had between July 1 and December 31, 2008 and then tell us the number of infections and hospitalizations.	**Number of Infections You Had During this Period (July 1 and December 31, 2008)**	**Did you receive or were you treated with intravenous antibiotics (given in the vein) for an infection as an outpatient (not in the hospital)?**	**Number of Hospital Admissions for Infections** *(Be sure to mark any hospitalizations on page 9)*
☐ Septicemia (sepsis, blood stream infection)	☐ 1 ☐ 2 ☐ 3 ☐ >3	☐ Yes ☐ No	☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Pneumonia, coccidiomycosis or other lung infection (not bronchitis or upper respiratory infections, ie. not "colds".)	☐ 1 ☐ 2 ☐ 3 ☐ >3	☐ Yes ☐ No	☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Pneumocystis, histoplasmosis, cytomegalic infections, blastomycosis, lysteria or listeriosis, aspergillosis, cryptococcus, nocardia, toxoplasmosis, cryptosporidiosis or any other fungal infection (**NOT** skin or nail infections)	☐ 1 ☐ 2 ☐ 3 ☐ >3	☐ Yes ☐ No	☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Skin infections (infected skin ulcer, cellulitis, infected nodules)	☐ 1 ☐ 2 ☐ 3 ☐ >3	☐ Yes ☐ No	☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Urinary tract infection / Kidney infection / Bladder infection	☐ 1 ☐ 2 ☐ 3 ☐ >3	☐ Yes ☐ No	☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Bone/Joint infection (osteomyelitis, septic joint, infected artificial joint)	☐ 1 ☐ 2 ☐ 3 ☐ >3	☐ Yes ☐ No	☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Influenza (Flu)	☐ 1 ☐ 2 ☐ 3 ☐ >3	☐ Yes ☐ No	☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Bronchitis	☐ 1 ☐ 2 ☐ 3 ☐ >3	☐ Yes ☐ No	☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Tuberculosis (TB)	☐ 1 ☐ 2 ☐ 3 ☐ >3		☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Cold or Upper respiratory illness (URI)	☐ 1 ☐ 2 ☐ 3 ☐ >3		☐ 1 ☐ 2 ☐ 3 ☐ >3
☐ Other, please specify ______________	☐ 1 ☐ 2 ☐ 3 ☐ >3		☐ 1 ☐ 2 ☐ 3 ☐ >3

If you were hospitalized during July 1 and December 31, 2008, did you develop an infection while you were in the hospital or during the 30 days after you were hospitalized? ☐ Yes ☐ No

Joint & Bone Medical Problems

- **Between July 1 and December 31, 2008** did you have a total joint replacement? ☐ Yes ☐ No
  If yes, please record joint replacements from July to December 2008 on page 9.
  Please select all appropriate answers. ☐ Hip ☐ Knee ☐ Shoulder ☐ Other ☐ None
- **Between July 1 and December 31, 2008** did you have joint resurfacing (not a joint replacement)? ☐ Yes ☐ No

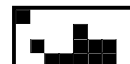
In the **last 6 months** were you diagnosed by a physician as having a fracture? ☐ Yes ☐ No

Mark the box of the bone(s) you fractured in the **last 6 months**.

☐ Fingers	☐ Ankle	☐ Neck	☐ Feet	☐ Hand	☐ Lower Leg	☐ Toes
☐ Wrist	☐ Hip	☐ Rib	☐ Lower Back	☐ Upper Arm	☐ Knee Cap	☐ Upper Leg
☐ Forearm	☐ Upper Back	☐ Elbow	☐ Shoulder	☐ Lower Arm	☐ Pelvis	☐ Head

- Not counting fractures that occured in the last 6 months, did you have any fractures in the **last 5 years**? ☐ Yes ☐ No

29200



The following questions ask whether you EVER had a condition.

These questions are repeated each time since we constantly get new patients and some things change that weren't caught before and since we can't customize our paper questionnaires, we do have to ask these questions every time.

Have you **EVER:**

Been diagnosed with Hepatitis A, B, or C? ☐ Yes ☐ No ☐ Don't know

If yes, what type? ☐ A ☐ B ☐ C ☐ I had hepatitis but don't know the type

Been diagnosed with Parkinson's Disease? ☐ Yes ☐ No

Had a **leg ulcer** in the area from the middle of your lower leg (midcalf) to your toes? ☐ Yes ☐ No

Had a high resolution CT-scan of the lungs? ☐ Yes ☐ No

Have you **EVER:**

Had an immunization for pneumonia (pneumovac)? ☐ Yes ☐ No

If yes, did you have your immunization in the last year? ☐ Yes ☐ No

If yes, did you have your immunization in the last 5 years? ☐ Yes ☐ No

Were you **EVER** told **by a Physician**:

- That arthritis (or lupus) has affected your lungs or that you have "rheumatoid lung"? ☐ Yes ☐ No
- That you had vasculitis? ☐ In the past ☐ Within the last 6 months ☐ Never

If yes, which part of your body was affected?

☐ Legs ☐ Feet ☐ Toes ☐ Arms ☐ Hands ☐ Fingers ☐ Other

Have you **EVER:**

Had a total joint replacement of the hip, knee or shoulder? ☐ Yes ☐ No

If yes, what was the year of the first surgery? ☐☐☐☐

What is the number of total joint replacement surgeries you have had (please check all that apply).

Hip	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ More than 4
Knee	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ More than 4
Shoulder	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ More than 4
Other	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ More than 4

Have you **EVER:**

Been diagnosed by a physician as having osteoporosis ("thinning of the bones") ? ☐ Yes ☐ No

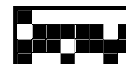
In the time before **July 1, 2008** did you ever have a side effect to:

A medication you took for arthritis? ☐ Yes ☐ No Any other medication not for arthritis or pain? ☐ Yes ☐ No

Did you have an immunization for influenza (flu) in 2008? ☐ Yes ☐ No

Did you have an immunization for zoster (shingles) in 2008? ☐ Yes ☐ No

63422



HOSPITALIZATIONS

PLEASE DO NOT LEAVE THIS PAGE BLANK!

Did you stay in the hospital overnight for any reason between July 1 and December 31, 2008? ☐ **Yes** ☐ **No**
If yes, please list all of those below.

Reason for Hospitalization	Hospital Name, City, State	Month Admitted	Number of nights in the hospital	Type of Stay: Medical	Type of Stay: Surgical
1)		☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ 1 ☐ 2-3 ☐ 4-6 ☐ 7-13 ☐ 14 or more	☐	☐
2)		☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ 1 ☐ 2-3 ☐ 4-6 ☐ 7-13 ☐ 14 or more	☐	☐
3)		☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ 1 ☐ 2-3 ☐ 4-6 ☐ 7-13 ☐ 14 or more	☐	☐
4)		☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ 1 ☐ 2-3 ☐ 4-6 ☐ 7-13 ☐ 14 or more	☐	☐

Between July 1 and December 31, 2008, have you been to a hospital emergency room (ER)? (Do not include after-hours clinics or urgent care centers) ☐ **Yes** ☐ **No**

If yes, how many total ER visits did you have? ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more

Between July 1 and December 31, 2008, were you a patient in a nursing or convalescent home or live-in rehabilitation center? ☐ **Yes** ☐ **No**

If yes, how many days did you spend in that center? ☐ 1-7 ☐ 8-14 ☐ 15-21 ☐ 22-28 ☐ More than 28

Between July 1 and December 31, 2008, have you had any outpatient surgery, endoscopy, gastroscopy or biopsy procedures? ☐ **Yes** ☐ **No**
If yes, please list all of those below:

Surgery/Procedure	Doctor's Name	Location and Address of Hospital or Doctor's Office	Month Procedure Done	Type of Procedure: Medical	Type of Procedure: Surgical
1)			☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐	☐
2)			☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐	☐
3)			☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐	☐

3390

CLINICAL HEALTH ASSESSMENT QUESTIONNAIRE (CLINHAQ)

We are interested in learning how your illness affects your ability to function in daily life. Place an X in the box which best describes your usual abilities OVER THE PAST WEEK:

Are you able to:	Without Any Difficulty	With Some Difficulty	With Much Difficulty	Unable To Do
Dress yourself, including shoelaces and buttons?	☐	☐	☐	☐
Shampoo your hair?	☐	☐	☐	☐
Stand up from a straight chair?	☐	☐	☐	☐
Get in and out of bed?	☐	☐	☐	☐
Cut your meat?	☐	☐	☐	☐
Lift a full cup or glass to your mouth?	☐	☐	☐	☐
Open a new milk carton?	☐	☐	☐	☐
Walk outdoors on flat ground?	☐	☐	☐	☐
Climb up five steps?	☐	☐	☐	☐

Please place an X in the box beside any aids or devices that you usually use for any of the above activities:

☐ Cane ☐ Crutches ☐ Walker ☐ Wheelchair ☐ Built up or special utensils ☐ Special or built up chair

☐ Devices used for dressing (button hook, zipper pull, long handled shoe horn) ☐ Other (please specify) ____________

Place an X in the box beside any categories for which you usually need HELP FROM ANOTHER PERSON:

☐ Dressing and Grooming ☐ Arising ☐ Eating ☐ Walking

We are also interested in learning whether or not you are affected by pain because of your illness.

How much pain have you had because of your illness in the past week? Place an X in the box that best describes the severity of your pain on a scale of 0-100.

NO PAIN **0** ☐ **100** SEVERE PAIN

How much trouble have you had with your stomach (i.e., nausea, heartburn, bloating, pain, etc.) in the past week? Place an X in the box that best describes the severity of your stomach problems on a scale of 0-100.

NO STOMACH PROBLEMS **0** ☐ **100** SEVERE STOMACH PROBLEMS

How much difficulty do you have with the following?	Without Any Difficulty	With Some Difficulty	With Much Difficulty	Unable to do
1) Ability to hear and understand what others are saying.	☐	☐	☐	☐
2) Ability to see and recognize people from a distance and/or to read a newspaper.	☐	☐	☐	☐
3) Ability to remember most things, think clearly and solve day-to-day problems.	☐	☐	☐	☐

Compared to 6 months ago, how would you rate your ability to function now?

☐ Much better now than 6 months ago ☐ Somewhat better now than 6 months ago ☐ About the same as 6 months ago

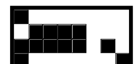
☐ Somewhat worse now than 6 months ago ☐ Much worse now than 6 months ago

Compared to 6 months ago, how would you rate your pain now?

☐ Much better now than 6 months ago ☐ Somewhat better now than 6 months ago ☐ About the same as 6 months ago

☐ Somewhat worse now than 6 months ago ☐ Much worse now than 6 months ago

24350



CLINICAL HEALTH ASSESSMENT QUESTIONNAIRE (CLINHAQ)

Place an X in the box which best describes your usual abilities OVER THE PAST WEEK:

Are you able to:	Without Any Difficulty	With Some Difficulty	With Much Difficulty	Unable To Do
Wash and dry your body?	☐	☐	☐	☐
Take a tub bath?	☐	☐	☐	☐
Get on and off the toilet?	☐	☐	☐	☐
Reach and get down a 5 pound object (such as a bag of sugar) from just above your head?	☐	☐	☐	☐
Bend down to pick up clothing from the floor?	☐	☐	☐	☐
Open car doors?	☐	☐	☐	☐
Open jars which have been previously opened?	☐	☐	☐	☐
Turn faucets on and off?	☐	☐	☐	☐
Run errands and shop?	☐	☐	☐	☐
Get in and out of a car?	☐	☐	☐	☐
Do chores such as vacuuming or yard work?	☐	☐	☐	☐

Please place an X in the box beside any AIDS or DEVICES that you usually use for any of the above activities:

☐ Bathtub bar ☐ Raised toilet seat ☐ Jar opener for jars previously opened ☐ Long-handled appliances for reach

☐ Long-handled appliances in bathroom ☐ Other (please specify) ____________

Please place an X in the box beside any categories for which you usually need HELP FROM ANOTHER PERSON:

☐ Hygiene ☐ Reach ☐ Gripping and Opening Things ☐ Errands and Chores

We are interested in knowing about any problems that you may have been having with fatigue. How much of a problem has fatigue or tiredness been for you IN THE PAST WEEK? Place an X in the box below that best describes the severity of your fatigue on a scale of 0-100.

FATIGUE IS NO PROBLEM **0** ☐ **100** FATIGUE IS A MAJOR PROBLEM

Are you able to:	Without Any Difficulty	With Some Difficulty	With Much Difficulty	Unable To Do
Go up two or more flights of stairs?	☐	☐	☐	☐
Do yard work (outside work or activities)?	☐	☐	☐	☐
Move heavy objects?	☐	☐	☐	☐
Lift heavy objects?	☐	☐	☐	☐
Wait in a line for 15 minutes?	☐	☐	☐	☐

Please place a checkmark in one box in each question below that best describes your own health state today.

1. ☐ I have no problems in walking about ☐ I have some problems in walking about ☐ I am confined to bed
2. ☐ I have no problems with self-care ☐ I have some problems washing or dressing myself ☐ I am unable to wash or dress myself
3. ☐ I have no problems performing my usual activities ☐ I have some problems performing my usual activities ☐ I am unable to perform my usual activities
4. ☐ I have no pain or discomfort ☐ I have moderate pain or discomfort ☐ I have extreme pain or discomfort
5. ☐ I am not anxious or depressed ☐ I am moderately anxious or depressed ☐ I am extremely anxious or depressed

49410

CLINICAL HEALTH ASSESSMENT QUESTIONNAIRE (CLINHAQ)

In general, would you say that your HEALTH NOW is: ☐ Excellent ☐ Good ☐ Fair ☐ Poor

Considering ALL THE WAYS THAT YOUR ILLNESS AFFECTS YOU, RATE HOW YOU ARE DOING on the following scale. Place an X in the box below that best describes how you are doing on a scale of 0-100.

VERY WELL **0** ☐ **100** VERY POOR

How much of a problem has sleep (i.e. resting at night) been for you IN THE PAST WEEK? Place an X in the box below that best describes how much of a problem sleep has been for you on a scale of 0-100.

SLEEP IS NO PROBLEM **0** ☐ **100** SLEEP IS A MAJOR PROBLEM

How satisfied are you with your HEALTH NOW?

☐ Very satisfied ☐ Somewhat satisfied ☐ Neither satisfied nor dissatisfied ☐ Somewhat dissatisfied ☐ Very dissatisfied

We are interested in learning how your illness affects your ability to function in daily life. Please place an X in the box which best describes your functional limitations OVER THE PAST WEEK on a scale of 0-100.

NO FUNCTIONAL LIMITATIONS **0** ☐ **100** SEVERE FUNCTIONAL LIMITATIONS

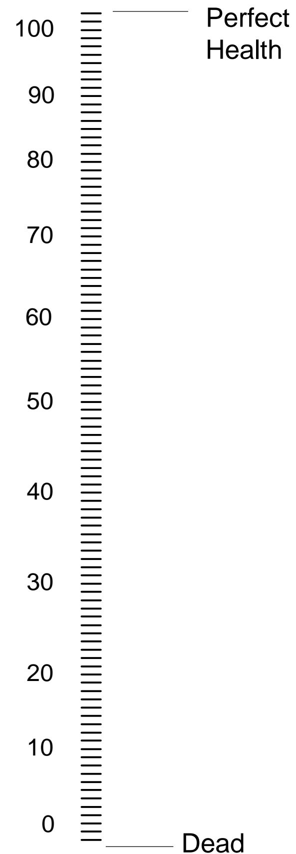
Considering ALL THE WAYS THAT YOUR ILLNESS AFFECTS YOU, how would you rate the severity of your disease?

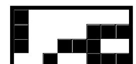
☐ No Symptoms ☐ Mild Severity ☐ Moderate Severity ☐ Severe Severity

HEALTH THERMOMETER

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state (perfect health) you can imagine is marked by 100 and the worst state you can imagine (death) is marked by 0.

We would like you to indicate on this scale how good or bad your own health is **today** in your opinion. Please do this by drawing a line through the point on the thermometer that best represents how good or bad your health state is, considering all aspects of your health and not just your arthritis or muscle problem.





SYMPTOMS

If you are stiff in the morning, about how long does the stiffness last?

☐ No stiffness ☐ Less than 30 min ☐ 30 min - 1 hr ☐ 1-2 hrs ☐ 2-4 hrs ☐ 4-8 hrs ☐ More than 8 hrs

During the PAST 6 MONTHS have you had any of the following symptoms?

If you have had none of these symptoms, place an X here: ☐

MUSCULOSKELETAL

- ☐ Swelling of hands, legs, feet or ankles (not due to arthritis)
- ☐ Joint pain
- ☐ Numbness/tingling/burning
- ☐ Joint swelling
- ☐ Low back pain
- ☐ Muscle pain
- ☐ Weakness of muscles
- ☐ Neck pain

GASTROINTESTINAL TRACT

- ☐ Loss of appetite
- ☐ Nausea
- ☐ Vomiting
- ☐ Heartburn
- ☐ Indigestion or belching
- ☐ Pain or discomfort in upper abdomen (stomach)
- ☐ Liver problems
- ☐ Pain or cramps in lower abdomen (colon)
- ☐ Diarrhea (frequent, explosive watery bowel movements, severe)
- ☐ Constipation
- ☐ Black or tarry stools (not from iron)
- ☐ Irritable bowel syndrome

CHEST, LUNGS AND HEART

- ☐ Wheezing (asthma)
- ☐ Chest pain
- ☐ Shortness of breath

URINARY SYSTEM

- ☐ Frequent urination
- ☐ Painful urination
- ☐ Pain, fullness or discomfort in the bladder region

HEAD, EYES, EARS, NOSE, MOUTH, THROAT

- ☐ Blurred vision or problems focusing
- ☐ Dry eyes
- ☐ Ringing in ears
- ☐ Hearing difficulties
- ☐ Mouth sores
- ☐ Dry mouth
- ☐ Loss, change in taste
- ☐ Tender lymph nodes
- ☐ Frequent sore throats
- ☐ Headache
- ☐ Dizziness
- ☐ Faintness
- ☐ Sensitivity to bright lights, loud noises, or odors
- ☐ Fever

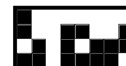
NEUROLOGICAL AND PSYCHOLOGICAL

- ☐ Tiredness (fatigue)
- ☐ Trouble thinking or remembering
- ☐ Depression
- ☐ Insomnia
- ☐ Nervousness (anxiety)
- ☐ Seizures or convulsions
- ☐ Fatigue severe enough to limit daily activity

SKIN

- ☐ Yellow skin or eyes (jaundice)
- ☐ Easy bruising
- ☐ Hives or welts
- ☐ Loss of hair
- ☐ Itching
- ☐ Red, white and blue skin color changes in fingers on exposure to cold or with emotional upset
- ☐ Rash
- ☐ Fluid-filled blisters
- ☐ Sun sensitivity (unusual skin reaction, not sunburn)

60057



JOINT/BODY PAIN

Please indicate below the amount of pain and/or tenderness you have had over THE PAST 7 DAYS in each of the joint and body areas listed below. Please make an X in the box that best describes your pain or tenderness. Be sure to mark both right side and left side separately. If you have had no pain or tenderness in a particular joint or body part, mark "None." There should be an answer for every joint or body part listed.

JOINTS	None	Mild	Mod	Severe	OTHER BODY AREAS	None	Mild	Mod	Severe
Shoulder, Lt.	☐	☐	☐	☐	Jaw, Lt.	☐	☐	☐	☐
Shoulder, Rt.	☐	☐	☐	☐	Jaw, Rt.	☐	☐	☐	☐
Elbow, Lt.	☐	☐	☐	☐	Lower Back	☐	☐	☐	☐
Elbow, Rt.	☐	☐	☐	☐	Upper Back	☐	☐	☐	☐
Wrist, Lt.	☐	☐	☐	☐	Neck	☐	☐	☐	☐
Wrist, Rt.	☐	☐	☐	☐					
Hand knuckles, Lt.	☐	☐	☐	☐	Upper arms, Lt.	☐	☐	☐	☐
Hand knuckles, Rt.	☐	☐	☐	☐	Upper arms, Rt.	☐	☐	☐	☐
Finger knuckles, Lt.	☐	☐	☐	☐	Lower arms, Lt.	☐	☐	☐	☐
Finger knuckles, Rt.	☐	☐	☐	☐	Lower arms, Rt.	☐	☐	☐	☐
Hip, Lt.	☐	☐	☐	☐	Upper leg, Lt.	☐	☐	☐	☐
Hip, Rt.	☐	☐	☐	☐	Upper leg, Rt.	☐	☐	☐	☐
Knee, Lt.	☐	☐	☐	☐	Lower leg, Lt.	☐	☐	☐	☐
Knee, Rt.	☐	☐	☐	☐	Lower leg, Rt	☐	☐	☐	☐
Ankle, Lt.	☐	☐	☐	☐	Head	☐	☐	☐	☐
Ankle, Rt.	☐	☐	☐	☐	Chest	☐	☐	☐	☐
Ball of foot, Lt.	☐	☐	☐	☐	Abdomen	☐	☐	☐	☐
Ball of foot, Rt.	☐	☐	☐	☐					
Heel, Lt.	☐	☐	☐	☐					
Heel, Rt.	☐	☐	☐	☐					
Foot arch, Lt.	☐	☐	☐	☐					
Foot arch, Rt.	☐	☐	☐	☐					

Do you have rheumatoid nodules (for example, bumps on your elbows caused by rheumatoid arthritis)? ☐ Yes ☐ No ☐ Don't Know

In general, how active was your arthritis or fibromyalgia from **July 1 and December 31, 2008**?
Place an X in the box below to indicate the amount of activity on a scale of 0-100.

NOT ACTIVE AT ALL **0** ☐ **100** EXTREMELY ACTIVE

In terms of joint tenderness and swelling, how active is your arthritis or fibromyalgia **TODAY**?
Place an X in the box below to indicate the amount of tenderness and swelling on a scale of 0-100.

NOT ACTIVE AT ALL **0** ☐ **100** EXTREMELY ACTIVE

ILLNESS RELATED EMPLOYMENT HISTORY

1. What is your current occupation? ______________________________
   (Please be specific. For example, math teacher, civil engineer, medical sales.)

2. Over your working life what was/is your main occupation? ______________________________
   (Again, please be specific.)

3. Currently, what is your main form of work? *(mark only one)* ☐ Paid Work ☐ Housework ☐ Student ☐ Retired ☐ Unemployed ☐ Disabled

4. Were you working for pay during the time you had your arthritis or pain problem? ☐ Yes ☐ No

5. Did you ever stop working permanently or retire early because of your arthritis or other pain? ☐ Yes ☐ No

6. Did you ever stop working permanently or retire early because of another medical reason? ☐ Yes ☐ No

If yes to #5 or #6, in what year? ☐☐☐☐

7. Which income group below comes closest to your total household income in the last year (January - December 2008) from **ALL SOURCES BEFORE TAXES?**

☐ Under $10,000	☐ $10,000 - 19,999	☐ $20,000 - 29,999	☐ $30,000 - 39,999	☐ $40,000 - 49,999
☐ $50,000 - 59,999	☐ $60,000 - 69,999	☐ $70,000 - 79,999	☐ $80,000 - 89,999	☐ $90,000 - 99,999
☐ $100,000 or more				

8. How many people, including yourself, live in your household? ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ More than 5

These next questions concern your usual activities. Usual activities are your work, whether or not you work for pay. If you are not working, usual activities mean self-care, housekeeping, volunteering or recreation.

9. **Please answer these questions whether or not you are working:**

   Between **July 1 and December 31, 2008** how many days did you have to **CUT DOWN** or **LIMIT** your usual activities (including housework, school)? ☐☐☐

   DURING THE PAST 30 DAYS:

   How many days did your health keep you from doing your usual activities? ☐☐ **(0-30 days)**

   How often were you able to perform your usual activities completely?
   ☐ All of the time ☐ Most of the time ☐ Some of the time ☐ A slight bit of the time ☐ None of the time

10. **Please answer this question ONLY if you are NOT WORKING:**
    How many days between **July 1 and Decemer 31, 2008** were you **COMPLETELY UNABLE** to carry out your usual activities BECAUSE OF YOUR HEALTH? ☐☐☐

11. **Please answer these questions only if you ARE WORKING:**

    How many days between **July 1 and December 31, 2008** were you unable to work BECAUSE OF YOUR HEALTH? ☐☐☐

    Did you stop working between **July 1 and December 31, 2008** DUE TO YOUR HEALTH? ☐ Yes ☐ No

    Did you reduce your hours of work between **July 1 and December 31, 2008** DUE TO YOUR HEALTH? ☐ Yes ☐ No

    Did you change jobs or place of work between **July 1 and December 31, 2008** DUE TO YOUR HEALTH? ☐ Yes ☐ No

12. In your lifetime have you **EVER** received Social Security **Disability** (Medicare disability) payments? ☐ Yes ☐ No
    This is NOT the same as Social Security retirement. This is a payment because you are disabled.

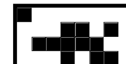
    If yes, what was the first year you received these payments? ☐☐☐☐ Was this due to arthritis? ☐ Yes ☐ No

13. During the time period **July 1 and December 31, 2008** did you receive any type of disability payments? ☐ Yes ☐ No

    If yes, please complete the section below.

Source of Disability Payment	Due to any reason?	Due to Arthritis?
Long term disability from employment	☐ Yes ☐ No	☐ Yes ☐ No
Social security disability payments or Medicare disability payments	☐ Yes ☐ No	☐ Yes ☐ No

15960



EMPLOYMENT ACTIVITIES

1. Are you currently doing any amount of paid work? ☐ Yes ☐ No
2. Some people work for a business owned by their family, but do not receive a paycheck. Do you do 15 hours a week or more of this work? ☐ Yes ☐ No
3. How many calendar weeks did you work in all your jobs in the last 6 months (July 1 - December 31, 2008)? (Please include paid vacation as weeks of work. There were 26 weeks during this time.)

   ☐☐ **WEEKS** worked

4. How many hours a week did you usually work in all your jobs in the last 6 months (July 1 - December 31, 2008)?

   ☐☐ **HOURS** per week

   If you can't give a number per week, give number of hours per month. ☐☐ **HOURS** per month

5. How much did you yourself earn from all your jobs in the last year (January-December 2008) BEFORE TAXES?

   ☐ Under $10,000 ☐ $10,000 - 19,999 ☐ $20,000 - 29,999 ☐ $30,000 - 39,999 ☐ $40,000 - 49,999

   ☐ $50,000 - 59,999 ☐ $60,000 - 69,999 ☐ $70,000 - 79,999 ☐ $80,000 - 89,999 ☐ $90,000 - 99,999

   ☐ $100,000 or more

MEDICATION COST INFORMATION

We would like to learn about the actual amount of money you spend directly on your health. You may or may not have health insurance that reduces the actual amount you spend, but for the questions below we are only interested in the amount you paid "out of pocket" for medical expenses not covered or reimbursed by insurance. If needed, please ask the person in your household who makes these payments to help you answer these questions.

1. What types of health insurance do you have at this time? (Place an X in the box next to ALL that apply)

   ☐ None ☐ Medicaid ☐ Medicare ☐ Medicare and HMO ☐ PPO ☐ Medicare Disability

   ☐ Private insurance company (like Blue Cross, Aetna, etc.) ☐ Health Maintenance Organization (HMO)

   ☐ Military Insurance ☐ Not sure

2. How much do you currently pay on average for one visit to your doctor? $ ________ **OR** ☐ Don't know
3. Between **July 1 and December 31, 2008**, approximately how much did you spend out of pocket on just your medications? $ ________ **OR** ☐ Don't know
4. If you're taking a biologic medication (Enbrel, Remicade, Anakinra, Humira, Orencia, or Rituxan), how much out of pocket did you pay for it **over the past 6 months**?

   $ ________ **OR** ☐ Don't know **OR** ☐ Not applicable

5. Between **July 1 and December 31, 2008**, approximately how much did you spend out of pocket on your medical expenses (this includes expenses for medication, doctor visits, x-rays, lab tests, hospitalizations and more)? Do not include what you paid for health insurance or any costs reimbursed by insurance.

   $ ________ **OR** ☐ Don't know

6. Drug, doctor and hospital costs may or may not be partially or fully paid by your insurance. How much of a financial problem are your drug and medical bills after receiving all insurance reimbursement?

   ☐ No problem or Limited Problem: I am able to pay the bills without much problem.

   ☐ A moderate problem: Paying the bills takes away some money I need for other activities.

   ☐ A great problem: I can't purchase all of the medications or medical care that I need.

7. Medical insurance costs may be paid by you or your employer. Do you or a family member pay all or part of your medical insurance? ☐ Yes ☐ No

   If yes, how much of a problem is paying your medical insurance? ☐ No problem ☐ Slight problem ☐ Moderate problem ☐ Great problem

MEDICATIONS

We are interested in ALL of the medicine you have taken in the PAST 6 MONTHS (**July 1, 2008 - December 31, 2008**). This includes both prescription and non-prescription medicines that you take for a health problem or to prevent a health problem This includes: your arthritis and pain-relieving medicines; stomach medicines; heart medicines; blood pressure medicines; cholesterol, insulin; hormones; topicals/creams, medicine for a headache or a "cold"; and "health food" type supplements like vitamins, herbs, and minerals. This would include things like glucosamine and chondroitin. In other words, all medications!

- **SPECIAL INSTRUCTIONS ABOUT INJECTIONS:** Include ALL injectable and infusion medications including Remicade, Humira, Enbrel, Kineret, Methotrexate, Rituxan, Orencia, Cortisone, Aristocort, Gold, Hyalgan, Synvisc, Prosorba treatments, Forteo, insulin and pain blocks.

  1. Place the injection size or the strength of the injection (if you know it) in the "Average Pill Strength" column. For example, for Methotrexate you might write .6 ml or .6 cc (injection size) or 15 mg (the strength).

  2. In the "Pills used per day" column tell us how often you take the injections if taken on a regular basis. Here are some examples that would work: 2 per week
3 per month
1 every 8 weeks
1 every 4 months

  Write in the number of injections AND the time period as shown above that best describes how you receive your injections.

- Include your arthritis medicines like Arava, Celebrex, Prednisone, Methotrexate (MTX), Gold, Plaquenil, Daypro, Etodolac, Relafen, Ibuprofen, and Naprosyn. **For oral Methotrexate (MTX) please indicate the number of pills used per week instead of per day.**
- Since some arthritis medicines may bother your stomach, please tell us about any stomach medicines that you take like Prevacid, Pepcid, Prilosec, Zantac, Tums, Tagamet, etc.
- Be sure to include medicines like Aspirin and Acetaminophen (Tylenol), or any medicines that contain Aspirin or Acetaminophen (Tylenol). When recording Aspirin, please tell us what type it is: for example, regular, enteric coated, buffered, etc.
- Also include pain medications like Ultram, Darvocet, and medicines like vitamin D, calcium, fluoride, estrogens, and osteoporosis drugs.
- If you are taking Methotrexate please indicate if it's a pill or an injection by writing "Methotrexate pill" or "Methotrexate Inj.".

Pages 17, 18, and 19 are for you to write in oral and injectable prescriptions and medicines.

If you had a side effect to any medicine you have taken between **July 1, 2008 - December 31, 2008**, please be sure to give us the details about that side effect on page 20-21. Also, if you stopped taking a medication, tell us why on page 22.

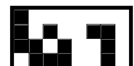
Mark here if you took NO medications from July - December 2008: ☐

Medicines Taken from July 1 - December 31, 2008

Drug Name *If injection or infusion see special instructions above **Please Print**	**Is this a prescrip-tion?**	**Average Pill Strength** **For injections or infusions see instructions**	**Average days used per month?**	**Pills Used Per Day** **For injections or infusions see instructions**	**Check any month used, even if only for one day**	**Were you still taking as of 12/31/08? (If no, see pg 22)**	**Did you start this medicine between July 1 and December 31, 2008?**	**Did you have a side effect to this medicine? (If yes, see pg 20 & 21)**
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

Continued on next page

19301

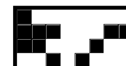


DRUGS CONTINUED **JULY 1- DECEMBER 31, 2008**

Drug Name **Please Print** *If injection or infusion see special instructions on pg 17.	Is this a prescrip-tion?	Average Pill Strength For injections or infusions see instructions	Average days used per month?	Pills Used Per Day For injections or infusions see instructions	Check any month used, even if only for one day	Were you still taking as of 12/31/08? (If no, see pg 22)	Did you start this medicine between **July 1 and December 31, 2008**?	Did you have a side effect to this medicine? (If yes, see pg 20 & 21)
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

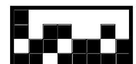
Continued on next page

9159



Drug Name **Please print** ***If injection or infusion see special instructions on pg 17.**	**Is this a prescrip-tion?**	**Average Pill Strength** **For injections or infusions see instructions**	**Average days used per month?**	**Pills Used Per Day** **For injections or infusions see instructions**	**Check any month used, even if only for one day**	**Were you still taking as of 12/31/08? *(If no, see pg 22)***	**Did you start this medicine between July 1 and December 31, 2008?**	**Did you have a side effect to this medicine? *(If yes, see pg 20& 21)***
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	☐ Yes ☐ No		☐ 1-10 ☐ 11-20 ☐ 21-31		☐ All ☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

46669



Drug Side Effects You Experienced between July 1 and December 31, 2008

We now need some additional information about any side effects that you marked on pages 17-19. Below and on the next page are spaces for side effects to four separate drugs. If you need more room, just write us a note and include it with this form when you send it back to us.

Drug causing side effect: 1) ______________________

Did you STOP the drug because of a side effect? ☐ Yes ☐ No

Did you change the dosage of the drug because of a side effect? ☐ Yes ☐ No

What side effects did you experience? Please list.

How SEVERE was each side effect?

1. ______________________ ☐ Mild ☐ Moderate ☐ Severe
2. ______________________ ☐ Mild ☐ Moderate ☐ Severe
3. ______________________ ☐ Mild ☐ Moderate ☐ Severe

Because of these side effects, did you have to: (mark all that apply) ☐ Take additional medicine ☐ Go to a doctor

If you are employed, how much time did you lose from work because of these side effects, if any?

☐ No time lost ☐ 1-3 days ☐ 4-7 days ☐ 8-10 days ☐ 11-20 days ☐ 21-30 days ☐ More than 30 days

What was the month that you first began experiencing the side effect(s) to this drug? ☐ Jul ☐ Aug ☐ Sep ☐ Oct ☐ Nov ☐ Dec

Do you still have any of these side effects? ☐ Yes ☐ No

About how long did the side effects last?

☐ Less than 1 week ☐ 1-3 wks ☐ 3-4 weeks ☐ 1-2 months ☐ 2-3 months ☐ 3-4 months ☐ 4-5 months ☐ 5-6 months

How certain are you that the above drug caused the side effects you described? ☐ Very certain ☐ Fairly certain ☐ A bit uncertain

Did the side effect(s) cause you to be hospitalized overnight or longer? ☐ Yes ☐ No *(Be sure to mark any hospitalizations on page 9)*

Drug causing side effect: 2) ______________________

Did you STOP the drug because of a side effect? ☐ Yes ☐ No

Did you change the dosage of the drug because of a side effect? ☐ Yes ☐ No

What side effects did you experience? Please list.

How SEVERE was each side effect?

1. ______________________ ☐ Mild ☐ Moderate ☐ Severe
2. ______________________ ☐ Mild ☐ Moderate ☐ Severe
3. ______________________ ☐ Mild ☐ Moderate ☐ Severe

Because of these side effects, did you have to: (mark all that apply) ☐ Take additional medicine ☐ Go to a doctor

If you are employed, how much time did you lose from work because of these side effects, if any?

☐ No time lost ☐ 1-3 days ☐ 4-7 days ☐ 8-10 days ☐ 11-20 days ☐ 21-30 days ☐ More than 30 days

What was the approximate month that you first began experiencing the side effect(s) to this drug? ☐ Jul ☐ Aug ☐ Sep ☐ Oct ☐ Nov ☐ Dec

Do you still have any of these side effects? ☐ Yes ☐ No

About how long did they last?

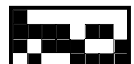
☐ Less than 1 week ☐ 1-3 wks ☐ 3-4 weeks ☐ 1-2 months ☐ 2-3 months ☐ 3-4 months ☐ 4-5 months ☐ 5-6 months

How certain are you that the above drug caused the side effects you described? ☐ Very certain ☐ Fairly certain ☐ A bit uncertain

Did the side effect(s) cause you to be hospitalized overnight or longer? ☐ Yes ☐ No *(Be sure to mark any hospitalizations on page 9)*

Continued on page 21

40303



Drug causing side effect: 3) ______________________________

Did you STOP the drug because of a side effect? ☐ Yes ☐ No
Did you change the dosage of the drug because of a side effect? ☐ Yes ☐ No

What side effects did you experience? Please list. How SEVERE was each side effect?

1. ______________________________ ☐ Mild ☐ Moderate ☐ Severe
2. ______________________________ ☐ Mild ☐ Moderate ☐ Severe
3. ______________________________ ☐ Mild ☐ Moderate ☐ Severe

Because of these side effects, did you have to: (mark all that apply) ☐ Take additional medicine ☐ Go to a doctor

If you are employed, how much time did you lose from work because of these side effects, if any?
☐ No time lost ☐ 1-3 days ☐ 4-7 days ☐ 8-10 days ☐ 11-20 days ☐ 21-30 days ☐ More than 30 days

What was the month that you first began experiencing the side effect(s) to this drug? ☐ Jul ☐ Aug ☐ Sep ☐ Oct ☐ Nov ☐ Dec

Do you still have any of these side effects? ☐ Yes ☐ No

About how long did the side effects last?
☐ Less than 1 week ☐ 1-3 wks ☐ 3-4 weeks ☐ 1-2 months ☐ 2-3 months ☐ 3-4 months ☐ 4-5 months ☐ 5-6 months

How certain are you that the above drug caused the side effects you described? ☐ Very certain ☐ Fairly certain ☐ A bit uncertain

Did the side effect(s) cause you to be hospitalized overnight or longer? ☐ Yes ☐ No *(Be sure to mark any hospitalizations on page 9)*

Drug causing side effect: 4) ______________________________

Did you STOP the drug because of a side effect? ☐ Yes ☐ No
Did you change the dosage of the drug because of a side effect? ☐ Yes ☐ No

What side effects did you experience? Please list. How SEVERE was each side effect?

1. ______________________________ ☐ Mild ☐ Moderate ☐ Severe
2. ______________________________ ☐ Mild ☐ Moderate ☐ Severe
3. ______________________________ ☐ Mild ☐ Moderate ☐ Severe

Because of these side effects, did you have to: (mark all that apply) ☐ Take additional medicine ☐ Go to a doctor

If you are employed, how much time did you lose from work because of these side effects, if any?
☐ No time lost ☐ 1-3 days ☐ 4-7 days ☐ 8-10 days ☐ 11-20 days ☐ 21-30 days ☐ More than 30 days

What was the month that you first began experiencing the side effect(s) to this drug? ☐ Jul ☐ Aug ☐ Sep ☐ Oct ☐ Nov ☐ Dec

Do you still have any of these side effects? ☐ Yes ☐ No

About how long did the side effects last?
☐ Less than 1 week ☐ 1-3 wks ☐ 3-4 weeks ☐ 1-2 months ☐ 2-3 months ☐ 3-4 months ☐ 4-5 months ☐ 5-6 months

How certain are you that the above drug caused the side effects you described? ☐ Very certain ☐ Fairly certain ☐ A bit uncertain

Did the side effect(s) cause you to be hospitalized overnight or longer? ☐ Yes ☐ No *(Be sure to mark any hospitalizations on page 9)*

For any of the medicines on pages 17-19 that you stopped taking between July 1 and December 31, 2008, please give us the additional information requested below.

Name of Drugs You Stopped Please Print	Why Stopped? (X all that apply)	Month stopped in 2008	Between July 1 and December 31, 2008, did you start another medicine to replace it?	If Yes, which Medicine? Please Print	Were you taking that medicine as of 12/31/08?
1.	☐ Didn't work ☐ Side effects ☐ Cost ☐ Other	☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	Yes ☐ No ☐		Yes ☐ No ☐
2.	☐ Didn't work ☐ Side effects ☐ Cost ☐ Other	☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	Yes ☐ No ☐		Yes ☐ No ☐
3.	☐ Didn't work ☐ Side effects ☐ Cost ☐ Other	☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	Yes ☐ No ☐		Yes ☐ No ☐
4.	☐ Didn't work ☐ Side effects ☐ Cost ☐ Other	☐ Jul ☐ Oct ☐ Aug ☐ Nov ☐ Sep ☐ Dec	Yes ☐ No ☐		Yes ☐ No ☐

Clinical Trials

Have you **Ever** been in a clinical trial for an **arthritis drug** (a clinical trial is a study where participants are given a drug to test to see if and how well it works)? ☐ Yes ☐ No ☐ Don't know

If yes, what was the name of the arthritis drug being tested? ____________________

During the last 6 months did you have a cortisone injection **into a joint**? ☐ Yes ☐ No

If yes, how many injections in the last 6 months? ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

22543

If you take any of the medications below please remember to report them on the Medications Section on pages 17-19.

Biologic medications, such as Remicade, Enbrel, Humira, Kineret, Orencia and Rituxan are a new class of medications for the treatment of rheumatoid arthritis. If you have used these medications for RA, we would like to learn about your experience with them.

Please check the medication you have most recently used: **(Check only one)**

- ☐ Remicade (Infliximab)
- ☐ Kineret (Anakinra)
- ☐ Enbrel (Etanercept)
- ☐ Humira (Adalimumab)
- ☐ Orencia (Abatacept)
- ☐ Rituxan (Rituximab)
- ☐ I have not used these medicines

After taking this medication,

Overall I was:	☐ Much better	☐ Somewhat better	☐ About the same	☐ Somewhat worse	☐ Much worse
My pain was:	☐ Much better	☐ Somewhat better	☐ About the same	☐ Somewhat worse	☐ Much worse
My function was:	☐ Much better	☐ Somewhat better	☐ About the same	☐ Somewhat worse	☐ Much worse
My fatigue was:	☐ Much better	☐ Somewhat better	☐ About the same	☐ Somewhat worse	☐ Much worse

---

If you took any biologic (Remicade, Orencia, Rituxan, Humira, Enbrel or Kineret) in the last 6 months please answer the following questions:

During the last 6 months did you have a reaction to an injection for Humira, Enbrel or Kineret?

☐ No ☐ Slight (some redness or minor pain) ☐ Moderate (moderate redness and/or pain)

☐ Severe (severe redness and/or pain) ☐ Immediate severe reaction requiring medical assistance

Which drug gave you the above reaction? ☐ Humira ☐ Enbrel ☐ Kineret

During the last 6 months did you have a reaction to an infusion (during or immediately after) for Remicade, Orencia or Rituxan?

☐ None ☐ Discomfort at infusion site ☐ Changes in blood pressure, felt ill, chills, felt faint

☐ Severe symptoms requiring medical care, such as severe fall in blood pressure, difficulty breathing or severe allergic raction

Which drug gave you the above reaction? ☐ Remicade ☐ Orencia ☐ Rituxan

---

Have you **EVER** had an injection site reaction to Humira, Enbrel or Kineret (rash, pain, itching, redness, swelling, hardness, bruising)? ☐ Yes ☐ No

If ***yes***, how severe was that reaction? ☐ Mild ☐ Moderate ☐ Severe

Did the reaction make you:

☐ stop the medication permanently ☐ stop the medication temporarily ☐ reduce the amount or frequency of the injections

If you are currently taking that medication, are you still having reactions? ☐ Yes ☐ No

If ***yes***, how severe was that reaction? ☐ Mild ☐ Moderate ☐ Severe

---

Have you **EVER** had an infusion site reaction to Remicade, Orencia or Rituxan (rash, pain, itching, redness, swelling, hardness, bruising)? ☐ Yes ☐ No

If ***yes***, how severe was that reaction? ☐ Mild ☐ Moderate ☐ Severe

Did the reaction make you:

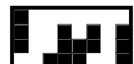
☐ stop the medication permanently ☐ stop the medication temporarily ☐ reduce the amount or frequency of the injections

If you are currently taking that medication, are you still having reactions? ☐ Yes ☐ No

If ***yes***, how severe was that reaction? ☐ Mild ☐ Moderate ☐ Severe

---

47529



SF - 36 HEALTH STATUS SURVEY

This survey asks for your views about your health now and in the past. This information will help us keep track of how you feel and how well you are able to do your usual activities.

Answer every question. If you are unsure of how to answer a question, please give the best answer you can.

In general, would you say your health is: ☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

Compared to 6 months ago, how would you rate your health in general now?

☐ Much better now than 6 months ago ☐ Somewhat better now than 6 months ago ☐ About the same as 6 months ago

☐ Somewhat worse now than 6 months ago ☐ Much worse now than 6 months ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?	**Yes, Limited A Lot**	**Yes, Limited A Little**	**No, Not Limited At All**
Vigorous activities, such as running, lifting heavy objects, participating in strenuous activities.	☐	☐	☐
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	☐	☐	☐
Lifting or carrying groceries.	☐	☐	☐
Climbing several flights of stairs.	☐	☐	☐
Climbing one flight of stairs.	☐	☐	☐
Bending, kneeling, or stooping.	☐	☐	☐
Walking more than a mile.	☐	☐	☐
Walking several blocks.	☐	☐	☐
Walking one block.	☐	☐	☐
Bathing or dressing yourself.	☐	☐	☐

During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

a. Cut down the amount of time you spent on work or other activities ☐ Yes ☐ No

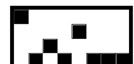
b. Accomplished less than you would like ☐ Yes ☐ No

c. Were limited in the kind of work or other activities ☐ Yes ☐ No

d. Had difficulty performing the work or other activities (for example, it took extra effort) ☐ Yes ☐ No

How TRUE or FALSE is each of the following statements for you?	**Definitely True**	**Mostly True**	**Not Sure**	**Mostly False**	**Definitely False**
a. I seem to get sick a little easier than other people	☐	☐	☐	☐	☐
b. I am as healthy as anybody I know	☐	☐	☐	☐	☐
c. I expect my health to get worse	☐	☐	☐	☐	☐
d. My health is excellent	☐	☐	☐	☐	☐

1040



During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

a. Cut down the amount of time you spent on work or other activities ☐ Yes ☐ No

b. Accomplished less than you would like ☐ Yes ☐ No

c. Didn't do work or other activities as carefully as usual ☐ Yes ☐ No

---

During the past 4 weeks to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

☐ Not at all ☐ Quite a bit
☐ Slightly ☐ Extremely
☐ Moderately

How much **bodily** pain have you had during the past 4 weeks?

☐ None ☐ Mild ☐ Severe
☐ Very mild ☐ Moderate ☐ Very severe

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

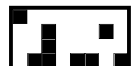
☐ Not at all ☐ Slightly ☐ Quite a bit
☐ Moderately ☐ Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. **How much of the time during the past 4 weeks:**	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of pep?	☐	☐	☐	☐	☐	☐
Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐
Did you feel worn out?	☐	☐	☐	☐	☐	☐
Have you been a happy person?	☐	☐	☐	☐	☐	☐
Did you feel tired?	☐	☐	☐	☐	☐	☐

During the past 4 weeks, how much of the time has your *physical health or emotional problems* interfered with your social activities (like visiting with friends, relatives, etc.)?

☐ All of the time ☐ Most of the time ☐ Some of the time
☐ A little of the time ☐ None of the time

1092



We need some information to keep our records current. We don't release this information to anyone. It is to help us keep track of you for mailing and telephone purposes.

Please list below the names and numbers of two people who don't live with you but are likely to know how to contact you.

1) Name ______________________

Area Code & Phone ☐☐☐ - ☐☐☐ - ☐☐☐☐

2) Name ______________________

Area Code & Phone ☐☐☐ - ☐☐☐ - ☐☐☐☐

Your Home Phone: ☐☐☐ - ☐☐☐ - ☐☐☐☐

Alternate Phone Number: ☐☐☐ - ☐☐☐ - ☐☐☐☐

Spouse's first name: ☐

Best time of day to call you: ☐

Please enter the last 4 digits of your Social Security Number. This enables the NDB to distinguish participants with similar names and home cities. It cannot be used to identify you in any way. ☐☐☐☐

E-mail address: (please print)

Please tell us the name of the doctor who is currently providing your arthritis care.

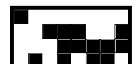
Dr. Name: ______________________

Dr. Address: ______________________

City ______________ **State** ______________ **Zip** ______________

If you have any comments, additional information or any problems that you think are important that we didn't ask about, please explain below.

63644



RELEASE OF MEDICAL INFORMATION

This page requests permission for us to review your medical records pertaining to your involvement in this research program. This information will be kept strictly confidential and used for research purposes only.

PLEASE USE INK AND PRINT

Name: ______________________________________ **Phone** (   ) ____________

Last **First** **Middle**

Address: ______________________________________

Street **City** **State** **Zip**

Birthdate: ____________ **Age:** ______ **Social Security Number:** ____________ **Optional**

Covering records from the period: 06/30/2008 through present. **Purpose of disclosure:** Long term outcome research in arthritis.

Information required: Any of the following with ICD coding of primary and secondary diagnoses

☐ Discharge Summary (procedure)____________ ☐ Biopsy Report (area) ____________

☐ Out Patient Report (procedure)____________ ☐ Other Report (procedure)____________

I understand that the information in my health record may include information relating to sexually transmitted disease, which may include, but are not limited to, diseases such as hepatitis, syphilis, gonorrhea, acquired immunodeficiency syndrome (AIDS), or human immunodeficiency virus (HIV). It may also include information about behavioral or mental health services and treatment for alcohol and/or drug abuse.

National Databank for Rheumatic Disease will not condition treatment, payment, enrollment or eligibility for benefits whether I sign the authorization.

Federal law protects the information disclosed pursuant to this Authorization. I understand that this information is confidential and will be used for research purposes only, and is not subject to redisclosure except for that allowed by law.

I have carefully read the above consent form and understand and know its contents. I have signed this consent of my own free will and consider myself bound by the provisions contained in the consent. I understand that I have the right to revoke (cancel) this authorization at any time by writing to Medical Records Acquisition, National Databank for Rheumatic Diseases, 1035 N. Emporia STE 288, Wichita, KS 67214 and that it will not apply to any information released before the written revocation is received. Upon the lapse of six (6) months from the date of signature this consent will automatically expire without my express revocation.

______________________________________ ____________

Signature of Patient or Legal Representative **Date**

____

Relationship if not signed by Patient

______________________________________ ____________

Witness **Date**

Office Use

This is to authorize that medical information regarding the above identified person be released:

FROM: ______________________________________

Name of Facility to Release Information

____

Address of Facility to Release Information

TO: **Deb Molina**
The Arthritis Research Center Foundation / National Data Bank for Rheumatic Disease
1035 N Emporia STE 288
Wichita KS 67214
Phone: 316-263-2125 **FAX: 316-263-0761**

PHOTOCOPY OF THIS AUTHORIZATION SHOULD BE TREATED IN THE SAME MANNER AS THE ORIGINAL

63200