

# **Bibliography of Resources**

## **I. Support Groups**

### **---ALS (Lou Gehrig's Disease)**

**1300 Wilson Blvd. Suite 600**

**Arlington, VA 22209**

**Phone:- (800) 782-4747**

### **---Upstate New York**

**135 Old Cove Road Suite 213**

**Liverpool, NY 13090**

**Phone:- (315) 413-0121**

**Website: ALS.org**

### **---Alzheimer's Association**

**225 N. Michigan Avenue Floor 17**

**Chicago, IL 60601**

**Phone:- (800) 272-3900 - 24/7 Helpline**

**Website: ALZ.org**

### **---Arthritis Foundation**

**1355 Peachtree Street NE Suite 600**

**Atlanta, GA 30309**

**Phone:- (800) 283-7800 (Helpline)**

**Website:- Arthritis.org**

**---American Cancer Society**

**Headquarters:-**

**250 Williams Street NW**

**Atlanta, GA 30303**

**Phone:- (800) 227-2345**

**Upstate New York Club:-**

**American Cancer Society Hope Club**

**(Capital Region, NY)**

**1 Penny Lane**

**Latham, NY 12110**

**Phone:- (518) 220-6960**

**Website:- [AmericanCancerSociety.org](http://AmericanCancerSociety.org)**

**---Celiac Disease Foundation**

**National Office:-**

**20350 Ventura Blvd. Suite 240**

**Woodland Hills, CA 91364**

**Main Phone: (818) 716-1513**

**Support Line:- (818) 716-1513 Ext. 104**

**Website:- [Celiac.org](http://Celiac.org)**

**---Crohn's Disease/Ulcerative Colitis**

**Crohn's and Colitis Foundation**

**733 Third Avenue Suite 510**

**New York, NY 10017**

**Phone:- (800) 932-2423**

**Website:- [Crohnscolitisfoundation.org](http://Crohnscolitisfoundation.org)**

**---Cystic Fibrosis**

**Cystic Fibrosis Foundation (National Office)**

**4550 Montgomery Avenue Suite 1100 N**

**Bethesda, MD 20814**

**Phone:- (800) 344-4823 {(800) FIGHT-CF}**

**Website:- CFF.org**

**---Diabetes**

**American Diabetes Association**

**2451 Crystal Drive Suite 900**

**Arlington, VA 22202**

**Phone:- (800) 342-2383 {(800)-DIABETES}**

**Website:- Diabetes.org**

**---Down Syndrome**

**National Down Syndrome Society (NDSS)**

**1155 15<sup>th</sup> Street NW Suite 540**

**Washington, DC 20005**

**Phone:- (800) 221-4602 (Also the Helpline)**

**Website:- NDSS.org**

**---Heart**

**American Heart Association**

**National Center:-**

**7272 Greenville Avenue**

**Dallas, TX 75231**

**Phone:- (800) 242-8721 {(800 AHA-USA-1)}**

**Website:- Heart.org**

**---Huntington's Chorea**

**Huntington's Disease Society**

**National Office**

**505 8<sup>th</sup> Avenue Suite 902**

**New York, NY 10018**

**Phone:- (212) 242-1968**

**Helpline:- (800) 345-4372 {(800 345-HDSA)}**

**Albany, NY Office**

**47 New Scotland Avenue**

**Albany, NY 12208**

**Phone:- (518) 262-6611 (Albany Medical Center Neurology Dept.)**

**Website:- HDSA.org**

**---Irritable Bowel Syndrome (IBS)**

**Website:- Irritablebowelsyndrome.org**

**---Kidney**

**Groups/Associations for Kidney**

- 1. American Association of Kidney Patients (AAKP)**  
**14440 Bruce B. Downs Blvd.**  
**Tampa, FL 33613**  
**Phone:- (800) 749-2257 {(800-749-AAKP)}**  
**Website:- AAKP.org**
- 2. Dialysis Patient Citizens (DPC)**  
**1001 Connecticut Avenue NW Suite 1230**  
**Washington, DC 20036**  
**Phone:- (202) 789-6931**  
**Website:- Dialysispatients.org**

3. **National Kidney Association**  
{The American Kidney Fund (AKF)}  
11921 Rockville Pike Suite 300  
Rockville, MD 20852  
**Phone:-** (800) 638-8299  
**Website:-** [Kidneyfund.org](http://Kidneyfund.org)
  
4. **Renal Support Network**  
1146 N. Central Avenue #121  
Glendale, CA 91202  
**Phone:-** (818) 543-0896  
**Website:-** [RSNhope.com](http://RSNhope.com)

[vf1]---**Lactose Intolerance**

**There is no “Official Website” or direct link for Lactose Intolerance.**

**However, the following websites can provide information on Lactose Intolerance (You need to type Lactose Intolerance in the Search Box in all of the websites):-**

- a. **Mayo Clinic – [mayoclinic.org](http://mayoclinic.org)**
- b. **The Cleveland Clinic – [clevelandclinic.org](http://clevelandclinic.org)**
- c. **Johns Hopkins Medicine - [hopkinsmedicine.org](http://hopkinsmedicine.org)**
- d. **National Institute of Health – [NIDDK.nih.gov](http://NIDDK.nih.gov)**
- e. **National Agricultural Library – [nal.USDA.gov](http://nal.USDA.gov)**

---**Liver**

**American Liver Foundation**

**PO Box 299**

**West Orange, NJ 07052**

**Helpline:-** (800) 465-4837

**Website:-** [liverfoundation.org](http://liverfoundation.org)

**---Lung**

**American Lung Association**

**National Office**

**55 W. Wacker Drive Suite 1150**

**Chicago, IL. 60601**

**Phone:- (800) 586-4872**

**Website:- lung.org**

**---Lupus**

**Lupus Foundation of America**

**2121 K Street NW Suite 200**

**Washington, DC 20037**

**Phone:- (202) 349-1155**

**Website:- lupus.org**

**---Lymphedema**

**National Lymphedema Network**

**PO Box 1008**

**New York, NY 10276**

**Phone:- (800) 541-3259**

**Website:- lymphnet.org**

**---Multiple Myeloma**

**The Multiple Myeloma Research Foundation**

**383 Main Avenue 5<sup>th</sup> Floor**

**Norwalk, CT 06851**

**Phone:- (203) 229-0464**

**Website:- TheMMRF.org**

**---Multiple Sclerosis (MS)**

**National Multiple Sclerosis Society**

**Greater New England Chapter**

**101A First Avenue Suite 6**

**Waltham, MA 02451-1115**

**Phone:- (800) 344-4867**

**Website:- [NationalMSSociety.org](http://NationalMSSociety.org)**

**Online Support Network:- [MyMSTeam.com](http://MyMSTeam.com)**

**---Muscular Dystrophy**

**Muscular Dystrophy Association---USA**

**161 N. Clark Suite 3550**

**Chicago, IL. 60601**

**Phone:- (800) 572-1717**

**Website:- [MDA.org](http://MDA.org)**

**---Paget's Disease of the Bone**

**There is no "Official Website" or direct link for Paget's Disease. However, the following websites can provide information on Paget's Disease of the Bone (You need to type in Paget's Disease of the Bone in the Search Box in all of the websites) :-**

**(NIAMS=National Institute of Arthritis & Musculoskeletal & Skin Diseases)**

- a. [NIAMS.nih.gov](http://NIAMS.nih.gov) [Arthritis.org](http://Arthritis.org) (there is NO period between gov and Arthritis but you must leave a space)**
- b. The Mayo Clinic - [mayoclinic.org](http://mayoclinic.org)**
- c. Johns Hopkins Medicine - [hopkinsmedicine.org](http://hopkinsmedicine.org)**
- d. NORD (National Organization for Rare Disorders) – [rarediseases.org](http://rarediseases.org)**
- e. The Cleveland Clinic - [clevelandclinic.org](http://clevelandclinic.org)**

**---Parkinson's Disease**

**Parkinson's Foundation**

**New York Address:- 1359 Broadway Suite 1509  
New York, NY 10018**

**Miami Address:- 200 SE 1<sup>st</sup> Street Suite 800  
Miami, FL 33131**

**National Helpline:- (800) 473-4636**

**Helpline Website:- [helpline@parkinson.org](mailto:helpline@parkinson.org)**

**Michael J. Fox Foundation for Parkinson's Research**

**Website:- [michaeljfox.org](http://michaeljfox.org)**

**---Shingles**

**Website:- [cdc.gov/shingles](http://cdc.gov/shingles)**

**---Stroke**

**American Stroke Association**

**National Center**

**7272 Greenville Avenue**

**Dallas, TX 75231**

**Phone:- (888) 478-7653 { (888) 4-STROKE }**

**Website:- [stroke.org](http://stroke.org)**



## **II. Community Resources**

**Community resources are different from community to community. Because of this, the best way to find out about available programs and services specific to a community is to contact agencies and bureaus that oversee these kinds of services.**

**The following is a limited list of some agencies that could assist in getting help for you and the person you are caring for. As I find out about other kinds of agencies that can offer help in regards to this, I will post updates on the BLOG.**

**The list is as follows:-**

**---Meals on Wheels America**

**Main Office**

**1550 Crystal Drive Suite 1004**

**Arlington, VA 22202**

**Phone:- (888) 998-6325**

**Website:- [mealsonwheelsamerica.org](http://mealsonwheelsamerica.org)**

**---Local Chamber of Commerce**

**---Local Senior Citizen Centers**

**---Local Churches**

**---Transportation Services Through:-**

- a. Senior Citizen Centers**
- b. Local Transportation Authority**
- c. Chamber of Commerce**

**---Local Community Social Services**

**---National Aging and Disability Transportation Center (NADTC)**

**Phone:-** (866) 983-3222

**Website:-** NADTC.org

**---U.S. Administration on Aging**

**Administration for Community Living**

**330 C Street SW**

**Washington, DC 20201**

**Phone:-** (202) 401-4634

**Website:-** ACL.gov

**---Elder Care Locator**

**Phone:-** (800) 677-1116

**Website:-** eldercare.ACL.gov

**---AARP (Association for The Advancement of Retired Persons)**

**Phone:-** (888) 687-2277

**Website:-** AARP.org

**---Hospice:-** Hospice is a service that can be arranged through:-

- a. Doctor's Office
- b. Social Worker in Hospital
- c. Visiting Nurse Agency (VNA) if VNA is seeing patient.

**---Landmark:** Landmark is a company that provides in home medical service that is offered by some health insurance companies to assist in the management of care at home for patients who have multiple medical issues. Contact your health insurance company to see if it offers Landmark and to ask if the person you are caring for qualifies for this service.