

Bibliography of Resources

I. Support Groups

---ALS (Lou Gehrig's Disease)

1300 Wilson Blvd. Suite 600

Arlington, VA 22209

Phone:- (800) 782-4747

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:-

270 Peachtree Street NW Suite 1300

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

---Celiac Disease Foundation

National Office:-

5850 Canoga Avenue 4th Floor

Woodland Hills, CA 91367

Main Phone: (844) 593-8169

Support Line:- (844) 593-8169 Ext. 104

Website:- 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

---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 15th 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 8th Avenue Suite 1402

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)

There is no official website for IBS. For information go to:

Mayoclinic.org Type in Irritable Bowel Syndrome (IBS)

---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 OR (866) 877-4242

Website:- Dialysispatients.org

1. **National Kidney Association**
{The American Kidney Fund (AKF)}
11921 Rockville Pike Suite 300
Rockville, MD 20852
Phone:- (800) 638-8299
Website:- Kidneyfund.org
2. **Renal Support Network**
1146 N. Central Avenue #121
Glendale, CA 91202
Phone:- (818) 543-0896 Toll Free: (866) 903-1728
Website:- RSNhope.com

---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**
- b. **The Cleveland Clinic – clevelandclinic.org**
- c. **Johns Hopkins Medicine - hopkinsmedicine.org**
- d. **National Institute of Health – NIDDK.nih.gov**
- e. **National Agricultural Library – nal.USDA.gov**
- f. **Lactaid.com---is a website maintained by the company which produces “Lactaid”; offering all kinds of information/suggestions on the subject and lists references ie. Mayo Clinic and Cleaveland Clinic.**

---Liver

American Liver Foundation

PO Box 299 **= Mailing Address**
West Orange, NJ 07052

155 Passaic Avenue Suite 100 **= Physical Address**
Fairfield, NJ 07004

Helpline:- (800) 465-4837

Website:- liverfoundation.org

---Lung

American Lung Association

National Office

55 W. Wacker Drive Suite 1150

Chicago, IL. 60601

Phone:- (800) 586-4872 / (800) LUNGUSA

Website:- lung.org

---Lupus

Lupus Foundation of America

2121 K Street NW Suite 200

Washington, DC 20037

Phone:- (202) 349-1155 OR (800) 558-0121

Website:- lupus.org

---Lymphedema

National Lymphedema Network

2229 Bridge Avenue PO Box 667

Point Pleasant, NJ 08742

Phone:- (800) 541-3259

Website:- lymphnet.org

---Multiple Myeloma

The Multiple Myeloma Research Foundation

383 Main Avenue 7th Floor

Norwalk, CT 06851

Phone:- (203) 229-0464

Website:- TheMMRF.org

---Multiple Sclerosis (MS)

National Multiple Sclerosis Society

733 Third Avenue

New York, NY 10017

Phone:- (800) 344-4867

Website:- NationalMSSociety.org

Online Support Network:- MyMSTeam.com

---Muscular Dystrophy

Muscular Dystrophy Association---USA

1016 W Jackson Blvd. #1073

Chicago, IL. 60607

Phone:- (800) 572-1717

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

---Parkinson's Disease

Parkinson's Foundation

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

Miami Address:- 5757 Waterford District Drive Suite 310
Miami, FL 33126

National Helpline:- (800) 473-4636

Helpline Website:- helpline@parkinson.org

Michael J. Fox Foundation for Parkinson's Research

Grand Central Station
PO Box 4777
New York, NY 10163-4777

Website:- michaeljfox.org

---Shingles

Website:- 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

I. 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

---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.