



## CAREGIVER SUPPORT

The following resources are provided for those caring for someone with MPS and ML. Many of the websites listed have online support groups you can join to get immediate advice, support, or understanding. Some of the sites have good advice for taking care of the caregiver. All of the resources listed can help you if you are feeling alone on your journey.

### **Family Caregiver Alliance**

Founded in 1977, Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. FCA now offers programs at national, state and local levels to support and sustain caregivers.

[www.caregiver.org](http://www.caregiver.org)

### **National Family Caregivers Association**

The National Family Caregivers Association (NFCA) supports, empowers, educates, and speaks up for the more than 50 million Americans who care for a chronically ill, aged, or disabled loved one. NFCA reaches across the boundaries of different diagnoses, different relationships and different life stages to address the common needs and concerns of all family caregivers.

[www.nfcacares.org](http://www.nfcacares.org)

### **The Courageous Parents Network**

CPN is a destination created by parents, for parents, to support, guide and strengthen families as they care for a seriously ill child. Here you will find wisdom from fellow parents and pediatric care providers to help you be the best parent you can be to your child and children—and get through each moment.

[courageousparentsnetwork.org/](http://courageousparentsnetwork.org/)

## **Caregiver Warrior**

Caregiver warrior Susanne White set up her website having cared for both of her parents. Along with guest bloggers, Susanne shares her tips to help caregivers take care of themselves, in order to be better prepared to care for their loved ones.

[caregiverwarrior.com](http://caregiverwarrior.com)

## **The Mighty**

The mighty is a digital health community created to empower and connect people facing health challenges and disabilities. There are over 2 million registered users. This site has articles written by patients and caregivers and is organized by topic. Try visiting the rare disease category.

[themighty.com](http://themighty.com)

## **Facebook Group Pages**

There are several group Facebook pages which are disease group specific. To find these online support groups, go to the Facebook search line and enter your child's syndrome. The following are examples of Facebook groups that are also easily searchable on Facebook:

Hunter Syndrome Awareness

Support Group for I-cell/Mucopolidosis II

ISMARD

MPS-1 Hurler's Syndrome

Morquio Syndrome

(MPS) Mucopolysaccharidosis

Sanfilippo syndrome/MPS III