# **Patient Resources**

AARDA does not have the resources to provide funds for patient or prescription assistance. However, the following is a list of organizations that may be able to provide help. The list provided is not extensive but is given as a starting point for those looking for support. AARDA does not endorse and is not affiliated in any way with these organizations.

#### 211 211.org 2-1-1

Supported by the United Way Worldwide, 2-1-1 is a toll-free service throughout the U.S. and some parts of Canada. Local community resource specialists provide confidential referrals and information on local health and human services.

#### ACR Assistance Program rheumatology.org/Portals/0/Files/Assistance%20Programs.pdf

From the American College of Rheumatology (ACR) a list of prescription assistance programs.

#### The PSI A.C.C.E.S.S. Program patientservicesinc.org/patients/access-program

Advocating for Chronic Conditions, Entitlements and Social Services (A.C.C.E.S.S.<sup>®</sup>) is a program dedicated to helping find solutions to the social and economic problems that confront families facing chronic conditions.

#### Clara Health clarahealth.com

Get Connected to the Right Clinical Trial. Clara is a fast, simple, most patient friendly way to connect autoimmune diseases patients to the newest treatment options.

#### Clinical Trials clinicaltrials.gov

ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world. Patients and their families can search and find available studies.

#### GoodRx goodrx.com

This is a website that provides comparison pricing for medications, as well as offers coupons for certain medications.

#### Healthwell Foundation healthwellfoundation.org 800-675-8416

HealthWell Foundation is an independent, non-profit organization that provides financial assistance to certain groups of insured patients living with chronic and life-altering illnesses to help them afford their medical treatments.

#### IG Living igliving.com

This is a magazine providing a wealth of information about immune globulin (IG). Its mission is to support the IG community through education, communication and advocacy. Providing information on insurance and insurance issues, education and studies, and legislation, "Ask the Expert" contact form, advocacy info, a blog, and a patient advocate.

#### Isabel- Symptom Checker symptomchecker.isabelhealthcare.com

Understand your symptoms. Developed from the professional Isabel Differential Diagnosis Generator used by doctors worldwide, the free Isabel Symptom Checker can help you make sense of and research your symptoms.

#### Lab Tests Online labtestsonline.org

Lab Tests Online is an award-winning health information web resource designed to help patients and caregivers understand the many lab tests that are a vital part of medical care.

#### My Good Days mygooddays.org 877-968-7233

My Good Days serves patients struggling with chronic disease, cancer, and other life-altering conditions. It offers progressive assistance programs, and financial support for patients who cannot afford the medications they need.

#### NORD rarediseases.org 203-744-0100, patient services 800-999-6673

The National Organization for Rare Disorders provides a wealth of information about rare diseases, along with information on insurance, advocacy, and events.

#### NeedyMeds needymeds.org 800-503-6897

NeedyMeds is a national non-profit organization that maintains a website of free information on programs that help people who can't afford medications and healthcare costs. It provides information on over 9,000 assistance programs, 15,000 free/low-cost/sliding scale clinics and nearly 1,500 drug discount coupons.

#### Partnership for Prescription Assistance pparx.org 888-477-2669

PPARx is sponsored by America's pharmaceutical research companies that connect low-income, underinsured, and uninsured individuals to more than 475 public and private patient assistance programs, including 180 programs offered by pharmaceutical companies.

#### Patient Advocate Foundation patientadvocate.org 800-532-5274, Co-pay relief program 866-512-3861

PAF is a national non-profit organization that provides professional case managers who negotiate with patients' insurers to resolve coverage and benefits issues. PAF also provides legal counseling and referral services for patients seeking to resolve debt crisis matters, and those confronting denial of insurance coverage, employment discrimination, or the need for negotiating support with public assistance programs through both state and federal agencies.

#### Prescription Process prescriptionprocess.com

A non-branded treatment access resource launched by the Alliance for Patient Access. This website provides information to understand what happens from the time a physician writes a script to the time it is dispensed at the pharmacy. It also helps to explain the prescription process and allows patients to share their experience with access issues, learn from others, advocate for important legislation, and stay current with the latest news.

#### The Patient Access Network Foundation panfoundation.org 866-316-7263

The Patient Access Network (PAN) Foundation helps federally and commercially insured people living with lifethreatening, chronic and rare diseases with the out-of-pocket costs for their prescribed medications, through over 50 disease-specific programs.

#### **<u>RxHope</u>** rxassist.org

RxHope is a comprehensive database of patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need.

<u>Support for Students</u> https://www.accreditedschoolsonline.org/resources/student-serious-illness/ Learning Options, Resources & Tips to Help Students Succeed in School

### Your local state representative congress.gov/state-legislature-websites

If you are looking for additional resources, consider contacting your local state representative. Your representative may have more resources and be more knowledgeable about local services that are available in your area. Your representative has a duty to serve his/her constituents.

# **Support Group Resources**

Support groups can be an invaluable source to patients living with autoimmune diseases.

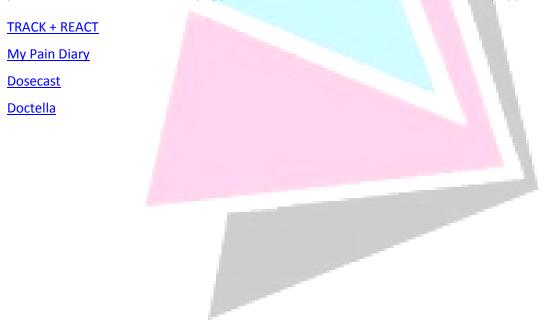
Support groups tend to be organized at the local level and be too varied for AARDA to keep a comprehensive list with accurate information. Therefore, we recommend contacting disease specific organizations, such as those in the <u>National</u> <u>Coalition of Autoimmune Patient Groups</u> (aarda.org/who-we-are/ncapg/)

Additionally, those searching for support groups can try these tips.

- Search social media sites to find online groups and forums.
- Contact health, religious, or other locally based organizations.
- Contact social workers or social services. These can be found at local hospitals.
- Contact your local hospital who may offer a general support group for persons with chronic illnesses. You may not sit next to someone with the same disease, but you may face the same types of challenges.

# **Patient Apps**

Technology can be a great asset in managing an illness and treatment. The following is a small sampling of apps you can use in order to keep track of things like medication and pain management. Please note that some apps may require purchase. These are not the only apps available, and AARDA does not endorse any app.



# Tips for finding a doctor

AARDA is not staffed by medical experts and cannot give recommendations or endorsements for any doctor. If you are looking for a doctor or specialist, the following are suggestions that can assist you.

- Contact your insurer for specialists within your network.
- Ask for a referral from a fellow patient.
- Contact your nearest teaching hospital. These can be connected to universities
- See whether the specialty you are looking for has a "find a specialist" search feature. For example,

Specialty	Name	Website
Endocrinology	American Association of Clinical Endocrinologists	https://www.aace.com/
Rheumatology	American College of Rheumatology	http://www.rheumatology.org/
Gastroenterology	American Gastroenterological Association	http://www.gastro.org/
Hematology	American Society of Hematology	http://www.hematology.org/
Neurology	American Academy of Neurology	https://www.aan.com/
Dermatology	American Academy of Dermatology	https://www.aad.org/
Pulmonology	American Thoracic Society	https://www.thoracic.org/
Nephrology	American Society of Nephrology	https://www.asn-online.org/
Ophthalmology	American Academy of Ophthalmology	https://www.aao.org/
Ear, nose, throat	American Academy of Otolaryngology	http://www.entnet.org/
OB/GYN	American Congress of Obstetricians and Gynecologists	http://www.acog.org/
Cardiology	American College of Cardiology Foundation	https://www.acc.org/
Immunology	The American Association of Immunologists	http://www.aai.org/
Urology	American Urological Association Education and Research	https://www.auanet.org/

For tips on getting a diagnosis please see:

http://www.aarda.org/wp-content/uploads/2013/08/Do-you-know-your-family-AQ -DoubleSided.pdf

### This list can be found online at:

https://www.aarda.org/who-we-help/patients/resources/

## **Contact AARDA**

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Updated 7/10/2019