

10th Annual Lupus Patient Education Day Resources for Your Best Care

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Last Updated: October 2nd, 2021

Goals of Presentation

- Provide information and resources for you to be able to help you assist yourself.
- Discuss Medication Resources
- Discuss Community Resources

Patient Assistance Programs

- Manufacturer supported programs that provide medication at no cost to patients who economically qualify for assistance when they have no other alternative with medication support.
 - High co-pays that are financially un-sustainable
 - Medicare D/Medicare Advantage programs – Coverage Gap
 - Most programs will support at below 500% Federal Poverty Level
 - Brand Name Medications that do not have a generic equivalent
 - Some Brand Name medications that are still supporting PAP programs
 - Infusion Drug Replacement programs for uninsured/under-insured
 - Dependent on patient interaction with the company to return calls to manufacturer and set up delivery of medication to home.

Co-Pay Assistance Cards

- Co-pay Assistance Cards from manufacturer for privately insured patients (Commercially Insured Patients)
 - Insurance through employers or those who have insurance through the marketplace
 - Federally insured patients do qualify
 - Medicare/Medicaid/Tri-Care Govt sponsored programs – do not qualify
 - Involve going to manufacturer website and signing up
 - Programs vary on the way the discount is applied
 - Some direct discount after pharmacy bills the co-pay card as a secondary insurance
 - Some programs require secondary billing and a specific credit-card supplied by the company

“Free Pharmacies”

- Pharmacies that can provide discounted medications to patients that financially qualify.
 - North Carolina MedAssist <https://medassist.org>
 - Limited Formulary of no-cost medications to patients
 - Statewide shipping

Discount Pharmacies

- Offer Medications at low-cost or specific cost program
 - RxOutreach <https://rxoutreach.org>
 - Limited Formulary
 - Hydroxychloroquine
 - \$16 for 30 tablets, \$32 up to 90 tablets
 - Brand Name Plaquenil
 - \$30 for 30 tablets and +\$5 for additional 30 tablets
 - Requires a letter of medical necessity for Brand Name Plaquenil

Community Resource Pharmacies

- Community Pharmacies that offer discounted or flat rates for medications (limited formulary)
 - Durham County – Project Access / Lincoln Heath
 - WelVista – South Carolina
 - Senior PharmAssist – Durham County (over 60 years old)
 - Piedmont Health <https://piedmonthealth.org>

Health System Pharmacies

- Depending on the Health Care System some discounted costs for medications for medications are offered to qualified patients (Prescriptions written by a provider at that Health System)
 - Duke Health Pharmacies – Very limited list of \$4.00 medications
 - MUSC Pharmacy – 340b low cost program
 - Other major health systems may have own version of these types of programs
 - Similarly- Community Health Clinics (often focusing on low income and uninsured folks) may have pharmacy assistance programs, which could be 340B pricing or free at some clinics
 - [Find a Health Center \(hrsa.gov\) www.findahealthcenter,hrsa.cov](http://www.findahealthcenter.hrsa.gov)

Pharmacy Discount Cards

- Programs that have downloadable coupons for discounted cost for Rx at site specific pharmacies (Cost may vary from pharmacy to pharmacy)
 - GoodRx
 - HelpRx
 - Script Save WellRx
 - RxSaver

Disease Specific Grant Programs

- Can only be used with patients that have some kind of prescription drug program
- Cover medication co-pays for specific medications on a disease list
- **Cannot** be used for all medications or other medication related costs
- Funding is limited and may not be available from year to year
 - HealthWell Foundation <https://www.healthwellfoundation.org>
 - TAF: The Assistance Fund (tafcares.org)
 - PAN Foundation: Find a disease fund - PAN Foundation

Miscellaneous Issues

- Compounded Medicaitons
 - Pharmacies cannot bill electronically to prescription insurance
 - Universal Claim Form to be obtained by patient from insurance and submit a manual claim (by the patient not the pharmacy) to insurance
 - Patient will need to pay up front for compounded medication
 - Re-imbusement may take several months (if insurance will cover at all)
 - Shop around compounding pharmacies regarding costs
 - Some items can be broken up and combined by patient (to have separate drugs charged to insurance)

Community Resources – Housing

- Low Income Housing Apartments – Find affordable rentals & housing options for low-income families and individuals.
<https://www.lowincomehousing.us>
- Local Housing Authorities
- Many homeless shelters also offer some case management assistance for people in the shelter to find more permanent housing
- Local Department of Social Services (DSS)—often a referral to other ongoing non-shelter resources needs to come from a DSS worker
 - Durham NC has coordinated Entry system for ALL housing
 - Charleston Area: The Navigation Center <https://thenavigationcenter.org/>

Community Resources – Utilities

- Office of Community Services – Low Income Home Energy Assistance Program (LIHEAP) <https://www.acf.hhs.gov/ocs/low-income-home-energy-assistance-program-liheap>
- **United Way 2-1-1 (1-888-366-3211)**: 2-1-1 is an information and referral service provided by United Way. Families and individuals can dial 2-1-1 or 1-888-892-1162 to obtain free and confidential information on health and human services and resources within their community www.211unitedway.org

Community Resources – Utilities

- Local Department of Social Services (DSS) often have emergency funds to help with utilities, medications, ect.
- Salvation Army: Exists to meet human need wherever, whenever, and however they can. www.salvationarmyusa.org
- Catholic Charities: To provide service to people in need, to advocate for justice in social structures, and to call the entire church and other people of goodwill to do the same. www.catholiccharitiesusa.org

Community Resources – Food

- WhyHunger (Why.) The WhyHunger Hotline refers people in need across the U.S. to food pantries, soup kitchens, summer meal sites, government programs and grassroots organizations, especially those that provide access to nutritious foods and nutritional support services. 1(800)5-HUNGRY 1-800-548-6479
<https://whyhunger.org/find-food/>
- United Way 2-1-1 Program
- Salvation Army
- Catholic Charities

Community Resources – Non-Emergency Medical Transportation

- All Medicaid plans have some non-emergency medical transportation benefit (specifics vary by plan/county/state)
- Some county Dept. of transportation offer it to non-Medicaid folks
- For seniors, some senior centers assist
- LogistiCare Member web site for South Carolina. Currently this site hosts information for members about how to get a ride if they have no other way to get a ride.

<https://memberinfo.logisticare.com/scmember>

Community Resources – Mental Health

- Psychology Today – Find a Therapist
<https://www.psychologytoday.com/us/therapists>
- [Lupus Support Online | Lupus Social Network - MyLupusTeam
www.mylupusteam.com](http://www.mylupusteam.com)
- <https://www.inspire.com/groups/lupusconnect/>
- [Find support near you | Lupus Foundation of America www.lupus.org](http://www.lupus.org)

Community Resources – Mental Health

- NC Crisis support: [NC DHHS: LME/MCO Directory](https://www.ncdhhs.gov/providers/lmemco-directory)
www.ncdhhs.gov/providers/lmemco-directory
- SC: [South Carolina Department of Mental Health](https://www.scdmh.net) www.scdmh.net
- National suicide prevention hotline: [Lifeline](https://www.suicidepreventionlifeline.org)
[\(suicidepreventionlifeline.org\)](https://www.suicidepreventionlifeline.org)

Community Resources - Primary & Dental Care

- Primary Care
 - <https://findahealthcenter.hrsa.gov>
 - Primary Care through larger health systems (also may access charity care)
- Dental Care
 - <https://www.freedentalcare.us>
 - NC MOM: North Carolina Dental Society Foundation Missions of Mercy (ncdental.org)
 - Dental Schools also offer discounted rates sometimes

Community Resources – Medical Center/School Associated Free Clinics

- National Associations of Free and Charitable Clinics:
<https://www.nafcclinics.org> - Great Website that you can search for care all over the United States
- UNC SHAAC: [Services Offered | SHAC: Student Health Action Coalition \(unc.edu\)](#)
- CARES Medical Clinic MUSC <https://muschealth.org/medical-services/cares/about>
- Fetter Health Care: www.fetterhealthcare.org
- SHIFA Clinic, SC <https://www.icnarelief.org/shifaclinics/>
- East Cooper Community Outreach: <https://eccocharleston.org>

Community Resources – Legal/Disability Help

- Free Legal Assistance

- South Carolina - <https://sclegal.org>
- North Carolina - <https://www.legalaidnc.org>
- Also consider checking with local State Bar associations which often have connection to explore limited pro-bono assistance

- Disability Advocates

- Social Security Disability Advocates of America (Veteran and Social Security Disability Help) <https://ssdaa.org>
- State Legal Aid Services often may assist AFTER an initial Denial
- National Social Security Disability Representatives www.Allsup.com

Community Resources – General Services for Disabled Individuals

- Get Care SC <https://www.getcaresc.com>
- Private Duty Nursing
- Personal Care Services through Medicaid benefits
- Elder Helpers is a user-friendly, web-based service. We believe that compassion at its finest is free. Volunteers register to offer their services based on their true desire to help elders. The Elder Helpers program strives to safely and conveniently connect these dedicated, passionate volunteers with elders in their local communities
www.elderhelpers.org
- Meals on Wheels www.mealsonwheelsamerica.org

Thank You

- Resources

Disease Specific Payment Assistance/Grant Programs

- Check each website often to see status of current fund applications (open, waitlist, closed). Status frequently changes.
- Different programs offer assistance for different disease states.
- Online application
 - Program will determine your eligibility
 - If determined eligible, will be offered payment assistance or a grant award depending on the program

Examples of Payment Assistance/Grant Programs

- Healthwell Foundation
 - <https://www.healthwellfoundation.org/disease-funds/>
 - Open Funds: New applications
 - Re-enrollment Funds: only for patients who have had and used a grant with HealthWell in the past three years
 - Grant with HealthWell will remain active for the entire 12-month grant cycle or until you have exhausted your allocated grant amount, whichever comes first.
- MyGoodDays
 - <https://www.mygooddays.org/patients/diseases-covered>
- NeedyMeds
 - <https://www.needymeds.org/>
- PAN Foundation
 - <https://www.panfoundation.org/find-disease-fund/>
- Patient Advocate Foundation- Co-Pay Relief
 - <https://copays.org/funds/>

Examples of Payment Assistance/Grant Programs

- Patient Assistance Programs, Medication Specific Assistance Programs - NORD (National Organization for Rare Disorders) (rarediseases.org)
 - <https://rarediseases.org/for-patients-and-families/help-access-medications/patient-assistance-programs-2/>
 - In addition to financial assistance, NORD offers travel assistance for clinical trials or consultation with disease specialists.
- Patient Services Inc
 - <https://www.patientservicesinc.org/>
 - Assist with copay, premium, ancillary, travel, and infusion costs
 - ACCESS program: provides free legal help for patients navigating the confusing fields of disability and health insurance.
- Relief Foundation- Scleroderma
 - <http://www.relief-foundation.org/mission.html>
 - http://www.relief-foundation.org/TRF_Financial_Aid_Application_1_.pdf
- The Assistance Fund
 - <https://enroll.tafcares.org/>
 - Waitlists are administered on a calendar-year basis. At the end of each calendar year, waitlist applications expire. Patients still seeking assistance must join waitlists for the subsequent calendar year.

Emergency Financial Assistance for Critical Health Issues

- Ellie's Army
 - <https://elliesarmy.org/apply-for-assistance/>
 - Assistance w/ medical expenses and emergency expenses for under age 30, with life threatening/critical health issues
- Help Me Bounce Back
 - <https://www.helpmebounce.org/apply-for-aid>
 - Families apply for aid on Help Me Bounce and are approved based on program guidelines. To begin their campaign, families create funding goals indicating what they are raising money for, for how much, and for how long.
 - Families then populate their profile with their story and their profile image. Once they are approved and their profile is live, families are able to blog and share their page with their network!

Support Group Examples

- Lupus Foundation of America
 - <https://www.lupus.org/resources/find-support-near-you>
 - Consists of chapters, offices, and support groups in communities throughout the United States.
- Rheumatoid Arthritis
 - <https://www.arthritis.org/liveeyes>
 - Virtual online chat and meetings
 - Tips to help manage
- Scleroderma
 - https://www.scleroderma.org/site/SPageServer/?pagename=patients_supportgroups#.YUy8rmZKg1g
 - Can find support groups based off region. Support groups offered to patients, newly diagnosed, friends/caregivers
- Sjogren's Syndrome
 - <https://www.sjogrens.org/living-with-sjogrens/support-groups-networks>
 - Over 65 groups throughout the US
 - Also offer Canadian, international, and special support groups
 - Special support groups include: 20s and 30s with Sjögren's, Men with Sjögren's, Pediatric, Spouses and Partners

Free Medicare Counseling

- Part B and D subsidies and plan options
 - SC: [South Carolina | State Health Insurance Assistance Programs \(shiphelp.org\)](https://shiphelp.org)
 - NC: [Contact Seniors' Health Insurance Information Program \(SHIIP\) | NC DOI](#)

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- [Find support near you | Lupus Foundation of America www.lupus.org](http://www.lupus.org)

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- National suicide prevention hotline: [Lifeline](https://www.suicidepreventionlifeline.org)
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