



ADVOCACY & POLICY REPORT

Accomplishments and Actions in 2022:
Advocacy, Policy & 50-State Network



2022

Steven Newmark, JD, MPA,
Director of Policy
www.ghlf.org

TABLE OF CONTENTS

OUR FOCUS

Page 03

2022 SNAPSHOT

Page 04

TEAM

Page 05

JANUARY

Page 08

FEBRUARY

Page 10

MARCH

Page 13

APRIL

Page 15

MAY

Page 17

JUNE

Page 19

JULY

Page 21

AUGUST

Page 24

SEPTEMBER

Page 25

OCTOBER

Page 26

NOVEMBER

Page 28

DECEMBER

Page 29

CONTACT US

Page 31

ACCOMPLISHMENTS & ACTIONS 2022 REPORT



Advocacy, Policy & 50-State Network

In 2022 we continued to educate our patients about advocacy issues impacting their well-being as well as incorporating patients' voices into our advocacy activities to ensure they are heard by key stakeholders across government and industry. Through outreach, education, and advocacy, we strive to create a world in which patients know that they are not alone and that their unique perspective is informing policymakers in the creation of health policy.

2022 ADVOCACY SPOTLIGHT

Federal and state comment and sign-on letters: **22**

Virtual meetings and testimony:

14 FEDERAL / 8 STATE

Individual legislator outreach

600+ CALLS AND EMAILS

Advocacy and policy podcast episodes:

67 WITH 15,000+ LISTENS

Topics covered:

**STEP THERAPY, COPAY ACCUMULATOR
ADJUSTORS, NON-MEDICAL SWITCHING**

**SUPPORTED 7 STATE BILLS THAT WERE
PASSED INTO LAW IN 2022**

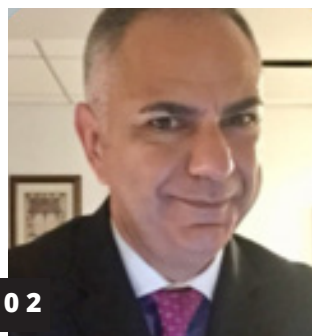
OUR ADVOCACY TEAM



01

STEVEN NEWMARK, JD, MPA
Director of Policy,
Chief Legal Officer

Steven Newmark oversees the policy and advocacy team. His vast experience in advocacy, and in particular vaccine-advocacy, has allowed GHLF to expand its reach into this important area. Steven's background in organizing has helped expand the size of the 50-State Network, and his legal background enabled GHLF to join in multiple litigations to protect patient access. Steven is responsible for identifying relevant issue areas and working with the Advocacy Team to craft responses to help patients. He was formerly Special Counsel to the President of NYC Health + Hospitals in New York City, and he served as the Senior Health Policy Adviser to New York City Mayor Bill de Blasio, as well as General Counsel in Mayor de Blasio's Public Advocate office. He was a Health Sciences Litigation Associate at Orrick, Herrington & Sutcliffe, LLP in New York City where he was part of the team that successfully defended the Vaccine Act before the Supreme Court in *Bruesewitz v. Wyeth*. He has been with GHLF since 2018.



02

ROBERT POPOVIAN, PHARM D, MS
Chief Science Policy Officer

Robert Popovian is a healthcare/biopharmaceutical leader in pharmaceutical science, business and government, with a distinctive array of academic and practical experience across a wide range of healthcare and business management functions. Positioned at the intersection of economics, policy, and innovation which maximizes patient access, Dr. Popovian fosters an environment of performance, leadership, inclusiveness and innovation. In 2021, he joined GHLF after spending more than 20 years with Pfizer. His last position was as Vice President, U.S. Government Relations. A trained clinical pharmacist and a health economist and policy expert, he helps GHLF raise the voices of patients through his Patient-Focused Economic and Health Policy Research group.



03

JOSEPH COE, MPA
Director, Education and
Digital Strategy

Joseph Coe has extensive knowledge and experience creating and sustaining grassroots and grasstops approaches to advocacy. He supports overall strategy and activation activities for our network. In addition, he oversees our migraine component of the 50-state network. And when breaking advocacy challenges or opportunities occur he is first into action: his team gets information quickly into the hands of patients and allied stakeholders via social media. Joe received his Master in Public Administration from Marist College and his undergraduate degree from the University at Albany, State University of New York. He was named one of the "40 under 40" by the Rockland County, New York Economic Development Corporation for his contributions to his local community and is also a recipient of the Public Citizen of the Year award given by the National Organization of Social Workers- NY State Chapter – Westchester Division for his social justice activism. He is a founding board member of the Phyllis B. Frank Rockland County Pride Center and currently serves as Vice Chair of their board and chair of the LGBTQ health committee. He is also a member of the Village of Haverstraw, NY, planning board and on the board of The Helen Hayes Hospital Foundation.



04

COREY GREENBLATT, MPH

Senior Manager, Policy and Advocacy

Corey Greenblatt manages the 50-State Network state policy priorities and works with advocates across the country to understand these policies and how they can use their voice to advocate on behalf of patients for change. Corey organizes meetings with legislators and members of the 50-State Network as well as patient-centered virtual programs such as the popular CreakyKitchen cooking show. He earned a Master of Public Health at Columbia University’s Mailman School of Public Health, with a focus in Healthcare Policy Analysis, and a Bachelor of Arts in International Studies and Public Health from the University of Miami. Corey has Type 1 diabetes, and prior to joining GHLF, he worked with the non-profit organization American Youth Understanding Diabetes Abroad (A.Y.U.D.A.) to provide outreach and education to children diagnosed with Type 1 Diabetes in Ecuador and the Dominican Republic.



05

ZOE ROTHBLATT, MPH

Associate Director, Community Outreach

Zoe Rothblatt engages in direct patient communications, legislative outreach and policy research. She is responsible for understanding patient needs and creating patient-centered resources so patients can stay informed on their condition and care. Along with researching current policy initiatives, Zoe conducts direct communication with legislators to advocate on behalf of patients. She earned a Master of Public Health at Columbia University’s Mailman School of Public Health, with a focus on Health Policy and Management. She received a Bachelor of Arts in Health: Science, Society and Policy from Brandeis University. Prior to joining GHLF, Zoe worked at the Community Service Society of New York as a community health advocate providing direct service, advocacy, advice and referrals for patients needing assistance.



06

CONNER MERTENS

Patient Advocate, Community Outreach Manager

Conner Mertens works as a liaison between patient advocates and stakeholders, ensuring patients have a voice in their care. He works directly with our 50-State Network members, empowering them to be their own best advocate, and providing tools and training to effectively advocate for positive change. Conner interned for the Minority House Leader at the Oregon State Legislature, worked closely with legislators in Washington State passing mental health and suicide prevention laws, and was an intern at CNN New York, working in production and research for Anderson Cooper 360. In 2014, he was the first National Collegiate Athletic Association (NCAA) football player to come out publicly about his sexuality.



07

ANGEL TAPIA

Senior Manager, Hispanic
Community Outreach

Angel Tapia drives research and education projects and leads culturally sensitive Spanish translations, original Spanish language material, multi-language social media platforms such as LinkedIn, Instagram and Facebook Español, and global disease-state efforts. Angel graduated from Golden Gate University with a degree in Business Marketing, and has held positions at the Ventura County Health Department in Ventura California, Christus Health in Katy, Texas, Unity Houston, One Halo Productions, and the Arthritis Foundation.



08

SARAH SHAW

Senior Manager, BIPOC
Community Outreach

Sarah Shaw covers the chronic disease community, including neurology, autoimmune conditions, and oncology. As a migraine patient she also implements migraine patient activities and coalitions, as well as GHLF/CreakyJoints patient councils. She holds a B.A. in Journalism & Media and a minor in Labor Studies with a concentration in Diversity in the Workplace from Rutgers University. She is very involved in patient advocacy events and has been featured in various advocacy campaigns, including the Speak Your Migraine Campaign, WebMD’s “In Their Own Words: Moving Beyond Migraine” segment with Robin Roberts and an avid advocate at Headache on the Hill in Washington, D.C.



08

JP SUMMERS

Patient Advocate, Community
Outreach Manager

JP Summers is responsible for onboarding our 50-State Network new members and managing patient-centered advocate initiatives. As someone living with multiple chronic illnesses and a caregiver to a son who was diagnosed with migraine disease, JP has navigated through unexpected barriers to obtain medical treatment for those health situations. It is through those circumstances she is able to channel awareness in her outreach, writing and state and federal legislator education. JP attended Texas Tech University, Lubbock, studying business and interior design. She is author of the romance novel, *The Storms That Faded Us*, which spent six months on the Amazon best seller list. She is a contributing writer for the Today Show Parenting Team and has hosted interviews at the NCAA Final Four basketball playoffs and Comic-Con.



GHLF continues to submit letters to policymakers around the country to help ensure patients who are their constituents have access to care without obstacles.

MONTH BY MONTH

JANUARY

Comment Letters:

1.26 – We wrote a letter to Senator Annette Cleveland, Committee Chair of the Washington State Senate Health Policy and Human Services Committee about legislation – SB 5532 - that would create a drug pricing review board. We asked questions about the creations of and intentions behind this review board to ensure it benefits patients.

[Read the letter about SB 5532](#)

1.26 – We wrote a letter in response to the Federal rule which sets the standard for health plans that are purchased through Medicare and Federal/State healthcare marketplaces.

[Read the letter about the federal rule](#)

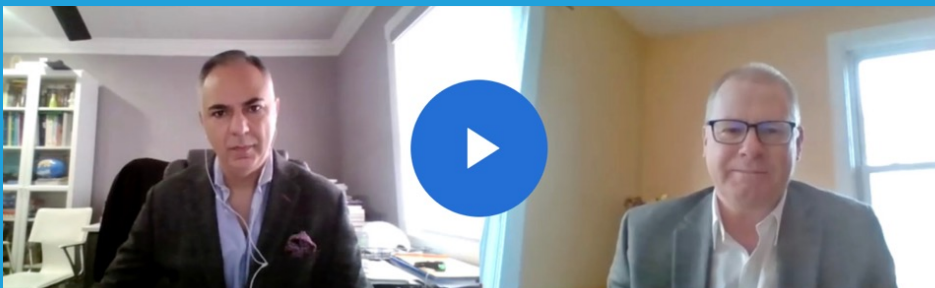


“
Through outreach,
education, and advocacy,
we strive to create a world
in which patients know that
they are not alone and that
their unique perspective is
informing policymakers in
the creation of health policy.



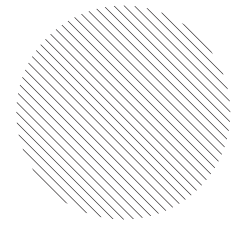
Media

Dr. Robert Popovian, Chief Science Policy Officer at GHLF shares some of the central issues of biosimilar access in the United States. [The Center for Biosimilars](#)



Podcasts

Omicron: An Excess of Selfishness. [The Health Advocates](#)
The Best Surprise, Is No Surprise. [The Health Advocates](#)
Free Tests and Best Masks. [The Health Advocates](#)
COVID Mandates at the Olympics. [The Health Advocates](#)
In Drug Development, It's About Time. [Healthcare Matters](#)
A Deep Dive Into COVID-19 Vaccines. [Healthcare Matters](#)



FEBRUARY

Comment Letters:

2.7 – We wrote a letter to the Centers for Medicare and Medicaid Services (CMS) stating our concerns with some of the specifics in the National Coverage Determination and the precedent that the Coverage of Evidence Development would set for other classes of medications, and further delay access to medications.

[Read the Letter About National Coverage Determination](#)

2.8 – We wrote a letter to Senator Annette Cleveland, Chair of the Health Policy and Human Services Committee, in support of Washington Senate Bill 5888. This legislation would ensure that patients can realize the full benefit of the deals and rebates that insurers and pharmacy benefit managers negotiate with drug manufacturers.

[Read the Letter About Washington Senate Bill 5888, Share the Savings](#)

2.8 – We wrote a letter to Senator Annette Cleveland, Chair of the Health Policy and Human Services Committee, in support of Washington Senate Bill 5610. This legislation would make it that all payments made through a copay assistance program would always count towards a patient's deductible and out-of-pocket maximums.

[Read the Letter About Washington Senate Bill 5610, Banning Copay Accumulator Adjustors](#)

VIRTUAL ADVOCACY

Each year, the Alliance for Headache Disorders Advocacy (AHDA) unites health professionals, migraine and cluster headache advocates and patients to present our requests or “asks” of Congress during the annual advocacy event Headache on the Hill. These asks are typically focused on improving awareness about the impact of headache disorders and the need for research funding. This month, the NJ Headache on the Hill team, met virtually with six different congressional offices to request funding to establish Indian Health Service (IHS) Headache Disorders Centers of Excellences (IHS HCoE). We met with:

- Senator Robert Menendez
- Senator Cory Booker
- Congresswoman Bonnie Watson Coleman
- Congressman William Pascrell
- Congressman Chris Smith
- Congressman Donald Norcross



PATIENT ADVOCACY

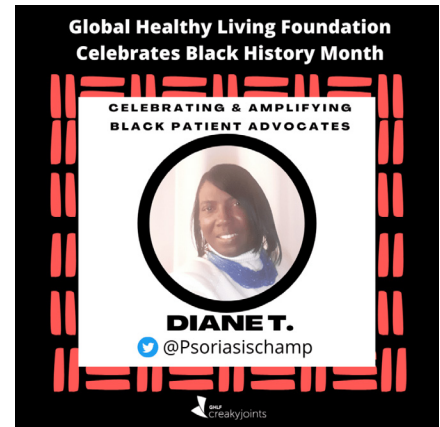
Sarah Shaw, BIPOC Patient Advocate, Community Outreach Manager at the Global Healthy Living Foundation, brought new voices to Headache on the Hill. Sarah referred and encouraged five BIPOC patients to apply for Headache on the Hill ([read more here](#)). Together, along with more than 200 other advocates, they asked Congress for:

1. Funding to establish Headache Disorders Centers of Excellences for Indigenous Communities
2. The National Institutes of Health (NIH) to prioritize research funding for diseases like migraine, which is chronically underfunded relative to its burdens



GHLF CELEBRATES BLACK HISTORY MONTH

During this Black History Month, we’re listening and learning as many of our members are discussing racial injustice and health disparities among Black patients with chronic illness, from rheumatic conditions to migraine to IBD to psoriasis and more. We spoke with GHLF members – who live with a wide range of chronic illnesses – about sharing their stories and speaking up for fellow patients in marginalized communities who too often feel voiceless. [Meet the advocates here.](#)



RAISING THE VOICE OF PATIENTS THROUGH AUDIO CONTENT

The Health Advocates: Extra Two-Part Special Episode

In the first of a two-part special, The Health Advocates are joined by Joe Coe, host of Talking Head Pain, to discuss how he had to battle with his insurance to get migraine medication. In the second episode, Corey Greenblatt, GHLF’s Manager of Policy and Advocacy, comes on to talk about how insurance companies harm patients and ways to advocate.

[Listen to Part One Here](#) | [Listen to Part Two Here](#)

Media

We Need to Avert the Next Public Health Disaster. [Inside Sources](#)

Podcasts

Too Soon To Be #OverCOVID. [The Health Advocates](#)

Living With The COVID Endemic. [The Health Advocates](#)

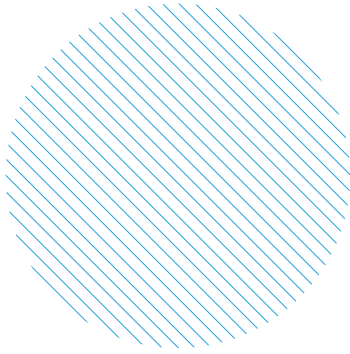
Disparities in Treatment for Migraine Patients. [The Health Advocates](#)

mRNA: COVID and Beyond. [The Health Advocates](#)

Status of COVID Treatments. [Healthcare Matters](#)

Patients Stuck with Health Care Deductible Bills. [Healthcare Matters](#)





MARCH

Comment Letters:

3.7 – We wrote a letter in support of the Center for Medicare and Medicaid Services (CMS) proposed changes to the definition of negotiated price and price concessions. These changes will help reduce some of the financial burden for patients in Medicare Part D.

[Read the letter about the negotiated price and price concessions](#)

3.10 – We signed on to a letter urging Congressional Appropriations Leaders to support supplemental funding to ensure access to sufficient supplies of essential medications that enable both prevention and treatment for COVID-19 patients.

[Read the letter about supplemental funding for COVID](#)

3.15 – We signed on to a letter to Senator Ron Wyden (D-OR) and Senator Mike Crapo (R-ID), asking to include the text of S.1943, the Increasing Access to Osteoporosis Testing for Medicare Beneficiaries Act of 2021, in any upcoming Medicare package approved by the Committee.

[Read the letter about the importance of affordable osteoporosis screening](#)

Virtual Advocacy:

We joined the Digestive Disease National Coalition’s 31st Annual Public Policy Forum to advocate for digestive disease research and improved patient care. In virtual meetings with Capitol Hill congressional offices, we shared our support for the Safe Step Act. We recently met with:

- Representative Joe Morelle
- Representative Paul Tonko
- Representative Andrew Garbarino
- Senator Chuck Schumer





MEDIA

Most Physicians Unable to Estimate Patient’s Out-of-Pocket Costs: How Pharmacists Can Help.
[Pharmacy Today](#)

Podcasts

After participating in the virtual meetings, we hosted two discussions on [The Health Advocates](#) podcast about our advocacy experience and how patients can get involved with our 50-State Network. In one episode we discussed [the power of virtual advocacy](#) with Corey Greenblatt, Senior Manager of Policy and Advocacy. In another, we [sat down with Dale Dirks](#) from the Digestive Disease National Coalition to talk about how patient stories can influence legislators to make change.

Calculating Risk, Staying COVID Safe.
[The Health Advocates](#)

COVID at 2: How We’ve Changed.
[The Health Advocates](#)

COVID Subvariant: Stay Vigilant My Friends.
[The Health Advocates](#)

Overcoming Years of Chronic Pain and Misdiagnoses.
[The Health Advocates](#)

UnQALYfied: Putting a Price on Patients Life.
[Healthcare Matters](#)



APRIL

Comment Letters

4.4 – We signed on to a letter to the Senate HELP Committee leadership and Senate E&C Committee urging to include in the Prescription Drug User Fee Act (PDUFA) Reauthorization provisions to strengthen the FDA’s accelerated approval pathway and enable patient access to these critical, often lifesaving therapies.

[Read the letter about the importance of accelerated approval](#)

4.22 – We wrote a letter to CDC Director, Rochelle Walensky, commenting on the draft guidance Proposed 2022 CDC Clinical Practice Guideline for Prescribing Opioids. We advocated for the CDC to consider the chronic disease patient perspective for this guidance.

[Read the letter about CDC Clinical Practice Guideline for Prescribing Opioids](#)

RAISING THE VOICE OF PATIENTS THROUGH AUDIO CONTENT

In a two-part special, the hosts of Healthcare Matters discuss what's behind non-medical switching, how it could harm patients, and what can be done to change this practice.

Non-Medical Switching: What It Is and How It Harms Patients

"It's Criminal" – Non-Medical Switching and Mental Health



PODCASTS

Patient Fight, Advocates Unite. [The Health Advocates](#)

Becoming a Health Advocate Through Grief. [The Health Advocates](#)

"Wear the Damn Mask." [The Health Advocates](#)

"We Grieve Who We Once Were." [The Health Advocates](#)

"It's Criminal" – Non-Medical Switching and Mental Health. [Healthcare Matters](#)

Why Are Drugs So Expensive for Seniors? [Healthcare Matters](#)

MEDIA

Upcoming Biosimilar Logjam Could Provide Cost Savings for Arthritis Drugs.

[Healio](#)

MAY

Comment letters

We wrote a letter and signed on to coalition letters to submit comments to the Federal Trade Commission (FTC) to inform the FTC on the role of Pharmacy Benefit Managers (PBMs) on patient access and affordability. We discussed ways that the FTC can help patient access and affordability.

Read the letters:

[Comments to FTC about PBM practices and impact on access and affordability](#)

[Comments to FTC about PBM practices and impact on access and affordability \(HIV + Hep Policy Institute Sign-On Letter\)](#)

[Comments to FTC about PBM practices and impact on access and affordability \(ATAP Sign-on Letter\)](#)

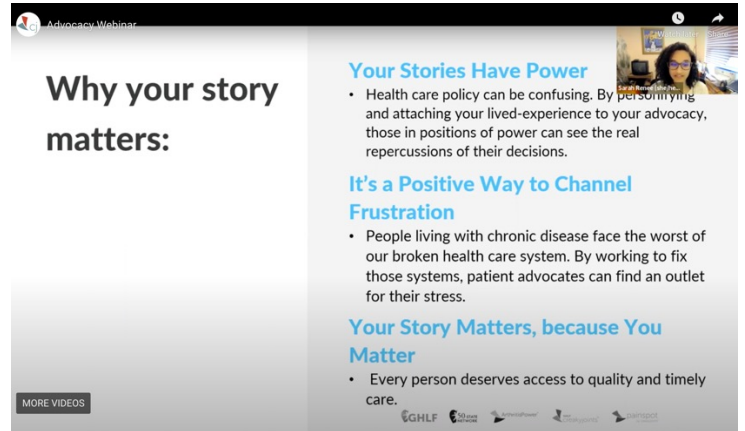
[Comments to FTC about PBM practices and impact on access and affordability \(ACCC Sign-On\)](#)



PATIENT ADVOCATES: THE IMPACT OF PATIENT STORIES

During our recent webinar, the GHLF advocacy team and patient advocates shared their insights on how to advocate and why diversity of stories and experiences is an essential tool for any successful patient advocacy initiative.

[Watch the webinar here](#)



TESTIMONY

Corey Greenblatt, Senior Manager of Advocacy at GHLF recently provided testimony to the Delaware Senate Banking, Business, and Insurance Committee to discuss Senate Bill 267, a copay accumulator adjustor ban. “I advocate for laws like this because we should be doing everything we can to make it easier for patients to access the medications that work for them, and copay assistance and this legislation do just that,” says Corey.

[Read the testimony](#)

MEDIA

Pharmacist-Administered Vaccinations Should Be Here to Stay.

[Governing](#)

Study: Empowering Pharmacists to Immunize Can Increase Vaccine Access, Reduce Health Disparities in Low-Income Communities.

[Pharmacy Times](#)

The Case for Expanding Pharmacists’ Authority to Administer Vaccines.

[Infectious Disease](#)

How Medicare Gets It Right and Wrong.

[Newsweek](#)

Podcasts

This Nerve-Wracking Time of COVID. [The Health Advocates](#)

The Alphabet of COVID and Why It Matters. [The Health Advocates](#)

Don’t Let Them Gaslight Your Health. [The Health Advocates](#)

It’s Time to Start Your Wellness Evolution. [The Health Advocates](#)

Overcoming the Hurdles of Biosimilar Adoption. [Healthcare Matters](#)

A Necessary Way to Expand Access to Health Care and Improve Equity. [Healthcare Matters](#)



JUNE

Comment Letters

6.1 – We signed on to a letter to the Vaccine and Related Biologic Products Advisory Committee in support of patient-centered care and patient access to appropriate treatments and therapeutics.

Read the letter to the FDA/VRBPAC

6.7 – We wrote a letter and signed on to a letter to Secretary Xavier Becerra requesting that the Department of Health and Human Services (HHS) take immediate action to maintain public health access to pandemic-related services at pharmacies.

Read the letter about protecting access to services at pharmacies

Letter to Secretary Becerra about maintaining public access to pandemic related services (NACDS sign-on)

Migraine and Headache Awareness Month

We talked to our patient community about what they wish others knew about migraine. @MissDS17 says “[I wish people knew about] The severity of chronic migraine — this is not just ‘she gets headaches.’ And how extremely easy it is to trigger a migraine. Tiny things loved ones can do to help you avoid triggers can be hugely helpful, especially avoiding certain sounds.”

Read more here

MIGRAINE AND HEADACHE AWARENESS MONTH

WHAT ARE THREE THINGS YOU WISHED OTHERS KNEW ABOUT MIGRAINE?

"Migraine is not just a garden-variety headache." - Prachi K.

"It affects all walks of life no matter age, gender, race, etc." - Sean M.

"Those with migraine can be significantly impaired making work, school, social obligations extremely difficult to manage." - Susan C.

GLOBAL HEALTHY LIVING FOUNDATION

Uplifting LGBTQ+ Patient Advocates

Sal Marx, a visual artist with ankylosing spondylitis, collaborated with patient advocates to create these graphics sharing their unique stories of what Pride means to each of them and what it's like navigating the health care system as queer people.

[Read more here](#)

“We have to love our community to want to create better space, opportunities, and lives for the people in it.”

— @Xtel007



PUBLICATIONS

Our peer reviewed paper published in [Health Science Journal](#) evaluating the 2022 national formulary of the second-largest PBM in the US found that nearly half (46%) of their 563 exclusions had questionable clinical or financial benefits to patients, meaning that prescribers are forced to select treatments that may have adverse financial or medical outcomes for their patients. The study also found that in some cases, the exclusions violate the core principle of a “formulary,” where lower-priced generics, authorized generics, or biosimilar should be preferred over equivalent brand name medicines.

Media

How to Get Better Migraine Care: Tips and Tools for BIPOC Community. [Healthline](#)
 Insurers and PBMs are Undermining Employee Health Benefits. [Healthcare Business Today](#)
 Biopharmaceutical Innovation Should be Championed. [Inside Sources](#)

Podcasts

Guess What We Learned at a Medical Conference? [The Health Advocates](#)
 New Test: Are You Immune to COVID? [The Health Advocates](#)
 When Is A Cold, Just A Cold? [The Health Advocates](#)
 Advocating for BIPOC and LGBTQIA+ Health Care. [The Health Advocates](#)



JULY

COMMENT LETTERS

7.14 – We wrote a letter to Texas Governor Greg Abbott urging him to inform pharmacists to continue distributing vital medications to patients with chronic illnesses without fear of prosecution.

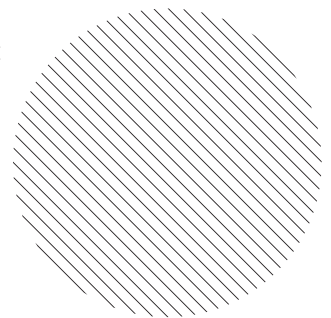
Read the letter about methotrexate access

7.22 - We signed on to a letter to Senator Cantwell to share our concerns about the Prescription Drug Pricing Reform proposal that was recently advanced in the U.S. Senate. If passed into law, the proposal will fundamentally reduce rare disease patients' ability to access care.

Read the letter to Senator Cantwell regarding rare diseases

7.25 - We signed on to a letter to Senator Cantwell and Grassley to support S.4293, the Pharmacy Benefit Manager Transparent Act of 2022.

Read the letter regarding the Pharmacy Benefit Manager Transparent Act



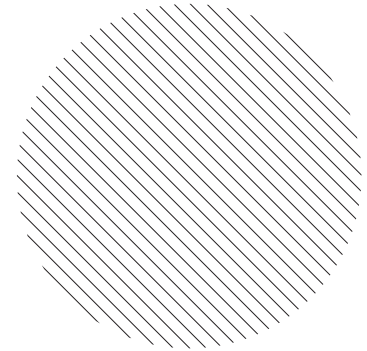
When patients lose access, we fight back

This month, we were concerned that patients across the country are facing issues accessing their methotrexate prescriptions. This is a result of the recent *Dobbs v. Jackson* decision, which effectively ended national access to legal abortion. Because methotrexate can be prescribed to treat ectopic pregnancies, this important medication is now being restricted in some states. GHLF became the loudest voice to protest this discriminatory and dangerous new barrier to medication access. In addition to identifying and supporting patients who told their stories to national media since early July through the end of the year, the Advocacy team has spoken with nearly two dozen reporters at national and international media outlets.

We gave interviews to Everyday Health, iNews UK, Time (picked up by Yahoo!, MSN.com, and featured on screen during an MSNBC segment), Bloomberg (picked-up by The Washington Post), BBC News Hour (which aired on 500+ stations in the United States and the U.K.), Medical News Today, Live Science (picked-up by Verve and other outlets), The Los Angeles Times (syndicated on the AP wire and ran in many local papers and was highlighted by Kaiser Health News), The Rheumatologist, Reuters (syndicated internationally, including on U.S. News, Globe & Mail (Canada) and Singapore Time), ABCNews.com (picked-up by radio station websites, particularly those with ABC affiliations), and The Independent (UK) (picked-up by Yahoo!).

Advocacy Alert: Abortion Bans Threaten Patient Access to Their Medications

We issued an advocacy alert to inform patients of methotrexate access issues and give opportunity to share concerns and stories. “Take the time you need to rest because our fight isn’t over! I know it’s exhausting to be constantly advocating for our own healthcare and well-being, but our chronic illness community depends on your voice,” says psoriatic arthritis patient advocate Madison Hartson on methotrexate access.





OTHER MEDIA

Pharmacists' Expanded Scope of Practice Here to Stay?
[Pharmacy Today](#)



DISABILITY AWARENESS

"The best thing my friends and family can do for me to combat ableism is to ask me how they can best accommodate me. It can be really frustrating navigating an extremely ableist society as a disabled person," writes patient advocate CarmenRose Fiallo. For Disability Pride Month, we talked to our patient community about what they wish others knew about being disabled, you can [check out the perspectives here](#).

PODCASTS

Methotrexate: Confusion and Controversy.

[The Health Advocates](#)

Patients Spark Action on

Methotrexate. [The Health Advocates](#)

We Have a Doctor in the House.

[The Health Advocates](#)

How Worried Should You Be of Monkeypox?

[The Health Advocates](#)



A
U
G
U
S
T**MEDIA**

In Low-Income Communities, Pharmacists Can Play a Critical Role in Vaccine Access. [ContagionLive](#)

In August, coverage of methotrexate access continued with GHLF spokespeople featured in [The Washington Post](#) (picked up by [Philadelphia Tribune](#), [Pittsburgh Post Gazette](#), and others), [KCBS-AM](#) (San Francisco), [Gay Sports News](#), [National Catholic Reporter](#), and [CBS Atlanta](#) (syndicated to many [local affiliates](#) across the country).

PODCASTS

Health Without Borders: Advocating for Rheumatoid Arthritis in the UK. [The Health Advocates](#)

Add to the Outbreaks: Polio. [The Health Advocates](#)

Methotrexate: Pharmacists Caught in The Middle. [The Health Advocates](#)

Fauci, the CDC, and Confidence in Public Health. [The Health Advocates](#)

“ *I have found that there are many gaps in our health care system and that there are large groups of people who aren't getting the care and treatment they need and deserve for many reasons, including poverty, stigmatization, and lack of self-worth. I wanted to raise awareness of that, work toward a solution, and be a voice for someone who couldn't use theirs,*” says Therese Lane. **[Read more here from our Canadian friends on why they advocate](#)**

CREAKYCHATS: “ACCESSIBILITY ANXIETIES”

Here's what our patient community shared about the challenges surrounding accessing consistent and quality treatments for chronic health conditions. “Access to tests, etc. are a real issue. You can't get the best treatment without diagnosis. I was told the average time to diagnosis for a rheumatological disorder like mine is six to eight years. Do they realize how long that is?” says rheumatoid arthritis patient advocate Michael Kuluva.

[Read more here](#)

PUBLICATIONS

The Relative Contributions of NIH and Private Sector Funding to the Approval of New Biopharmaceuticals.

[Therapeutic Innovation & Regulatory Science](#)

PODCASTS

Project Wheelchair Runway

[The Health Advocates](#)

The COVID-19 Pandemic: A Marathon with the Finish Line in Sight?

[The Health Advocates](#)

It's Complicated: Inflammatory Bowel Disease Diagnosis and Treatment.

[The Health Advocates](#)

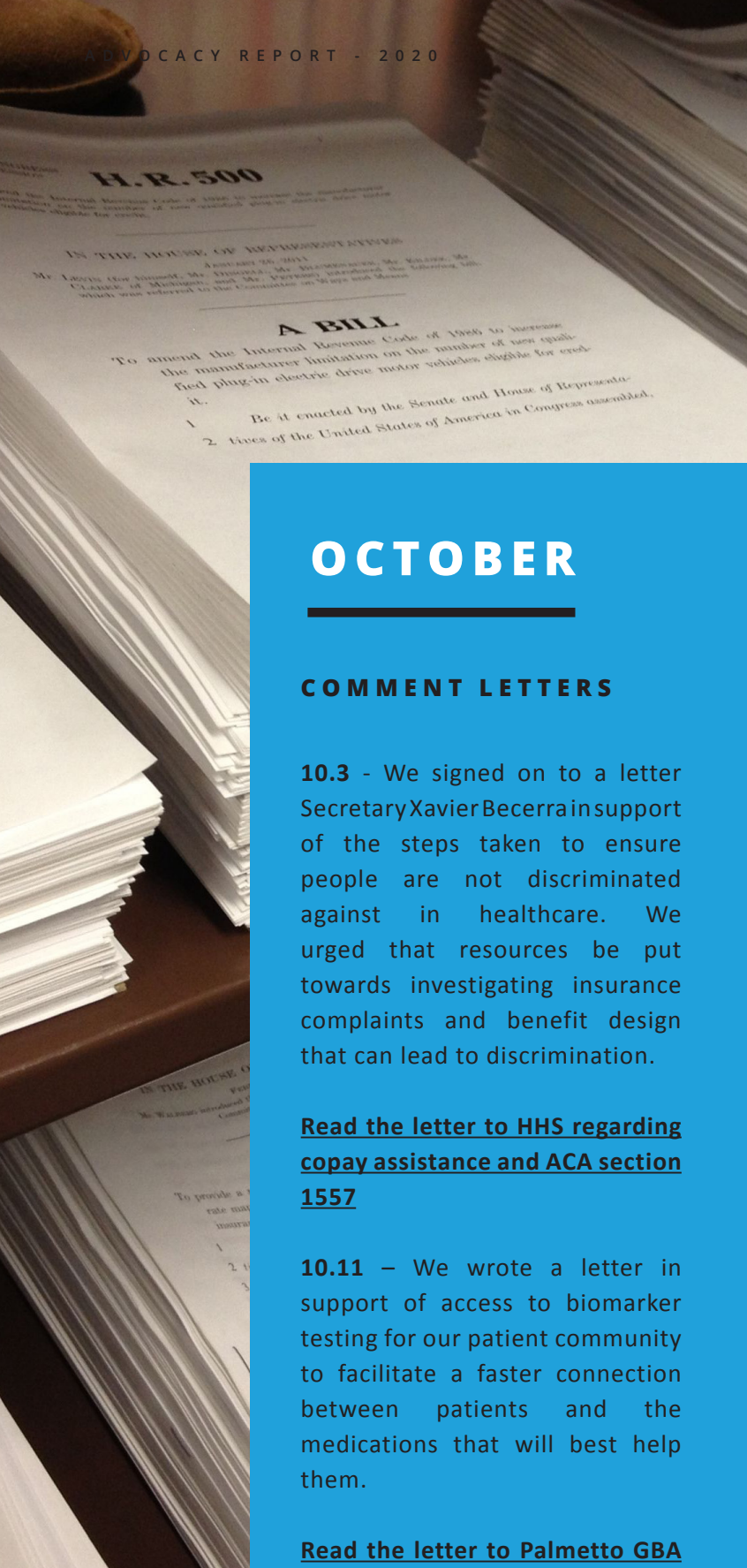
The Inflation Reduction: the Good, the Bad, and the Ugly – What's In It for Patients?

[Healthcare Matters](#)

A Failed Promise: Why Overpaying for Generic Medications? [Healthcare Matters](#)

MEDIA

In September and early October, methotrexate access coverage included [Get Me Giddy](#), [Everyday Health](#), [Guardian](#), [Politico](#) (picked-up by several [political websites](#)), and [USA Today](#) (picked-up by Yahoo!). The organization also spoke on background to other reporters, which may lead to future coverage, such as Vice Media.



OCTOBER

COMMENT LETTERS

10.3 - We signed on to a letter Secretary Xavier Becerra in support of the steps taken to ensure people are not discriminated against in healthcare. We urged that resources be put towards investigating insurance complaints and benefit design that can lead to discrimination.

[Read the letter to HHS regarding copay assistance and ACA section 1557](#)

10.11 – We wrote a letter in support of access to biomarker testing for our patient community to facilitate a faster connection between patients and the medications that will best help them.

[Read the letter to Palmetto GBA regarding coverage for biomarker testing](#)

THREE PROPOSED BILLS AIMED AT IMPROVING RHEUMATOLOGY CARE

Rheumatology leaders and patient advocates convene Capitol Hill to advocate for legislation to improve patient access to care.

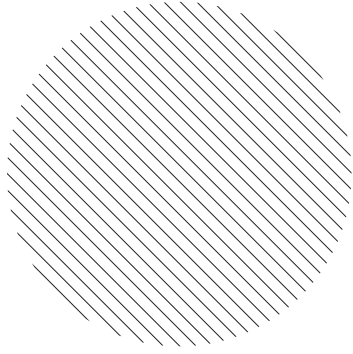
[Read about the bills](#)

ALL COPAYS COUNT COALITION HILL DAY

We participated in the All Copays Count Coalition Hill Day which brought together a group of 80 national non-profit, non-partisan patient advocacy and provider organizations representing millions of people living with chronic illness. During the virtual meetings, we raised awareness of copay accumulator policies in insurance plans and explained how they hurt patients. We asked Senators to champion the HELP Copays Act ([HR5801](#)) by introducing a companion bill. We met with:

- Senator Marsha Blackburn (R-TN)
- Senator Mike Braun (R-IN)
- Senator Bob Casey (D-PA)
- Senator Tammy Duckworth (D-IL)
- Senator John Hickenlooper (D-CO)
- Senator Mark Kelly (D-AZ)
- Senator Patty Murray (D-WA)
- Senator Tim Scott (R-SC)
- Senator Krysten Sinema (D-AZ)

GHLF’s Patient Advocate and Community Outreach Manager, JP Summers shared, “As someone who experienced issues due to a copay accumulator adjuster program during the early stages of my chronic illness diagnosis then again, a few months later when my son became chronically ill, it was important to share how our household went through the financial, medical, and emotional burden of these unnecessary practices.”



Podcasts

“Patient Stories Move The Needle” – Nathaniel Brown from the Chronic Disease Coalition. [The Health Advocates](#)

COVID-19: As the Virus Wanes, Many Questions Remain. [The Health Advocates](#)

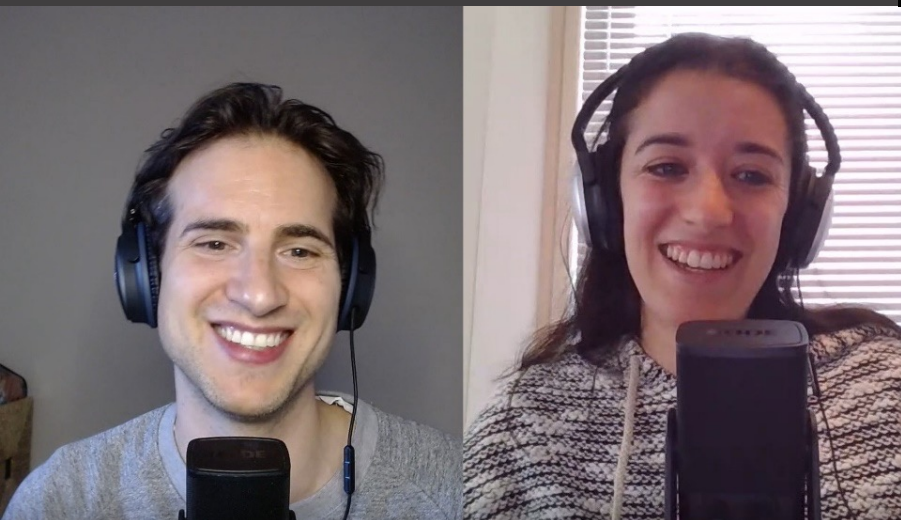
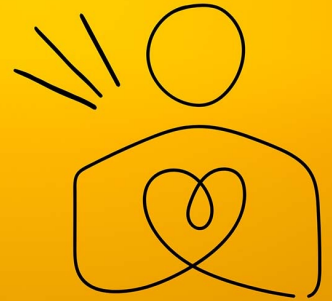
Vaccine Skepticism: A Worrisome Trend Beyond COVID-19. [The Health Advocates](#)

Copay Accumulators Explained: Why Advocacy Matters. [The Health Advocates](#)

The 340B Program: Is this Drug Discount Initiative a Victim of its Own Success? [Healthcare Matters](#)

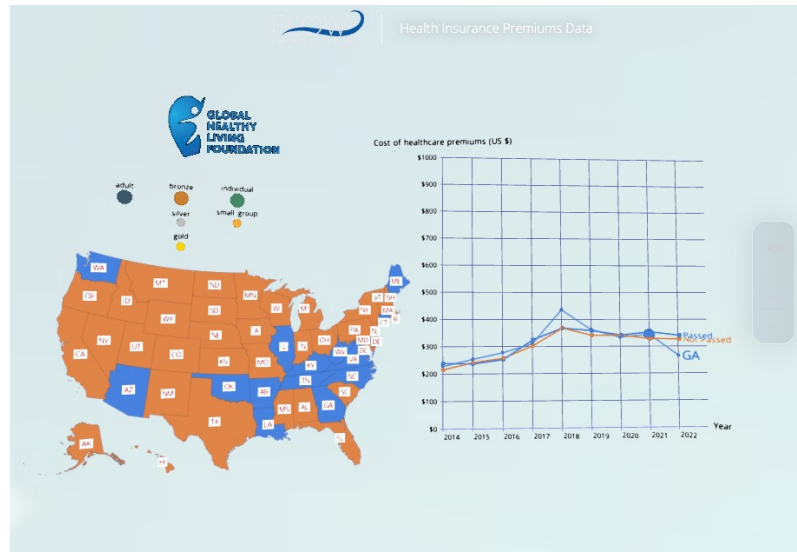
‘Living with COVID’: Where Do We Go from Here? [Healthcare Matters](#)

THE Health Advocates



NOVEMBER

We launched a free, [interactive tool](#) that will provide legislators, policy makers, and interested parties with objective data demonstrating how U.S. health insurance premiums have fluctuated since 2014. GHLF analysis shows that, to date, there has been no statistically significant change in the rates of health insurance premium increases after the passage of state laws requiring that patient assistance funds count toward policyholders’ deductibles or out-of-pocket (OOP) maximum payments.



Media

How Do Patient Assistance Programs Work? The Pros and Cons of Prescription Coupons and More. [USA Today](#)
 Is Prescription Copay Assistance Contributing to Rising Drug Prices? Why Buyers Should Beware. [USA Today](#)
 Reducing Vaccine Hesitancy in Patients with Autoimmune Diseases. [Rheumatology Network](#)
 People of Color Face Discrimination in Diagnosis and Treatment of Migraines, Advocates Say. Why?
 What Is the Value of Interchangeability Designation for a Biosimilar? [The Center for Biosimilars](#)

Podcasts

Cancer Fashionista: Advocating in Style. [The Health Advocates](#)
 The 2022 Midterm Elections: A Hot Take on What’s at Stake. [The Health Advocates](#)
 EXTRA Part 1 – Non-Radiographic Axial Spondyloarthritis: A Conversation with Dr. Jeff Stark and Patient Advocate Ricky White. [The Health Advocates](#)
 ACR Convergence: Key Takeaways from the World’s Premier Rheumatology Conference. [The Health Advocates](#)
 Talking Turkey Day and COVID. [The Health Advocates](#)
 The 2022 Midterms: What to Expect for Health Care Policy. [Healthcare Matters](#)





DECEMBER

On December 6th, Lou Tharp and Robert Popovian were joined by Terry Wilcox from Patients Rising for a roundtable discussion on legislative priorities facing patients in 2022. They covered topics including step therapy, transparency for pharmacy benefit managers, and the 340b federal program.

RAISING THE VOICE OF INFLAMMATORY BOWEL DISEASE PATIENTS

During Crohn's and Colitis Awareness Week, we spoke with eight inspiring warriors who are living their best lives despite the challenges of IBD. The advocates shared their daily struggles with IBD – and why advocacy and community have become crucial to their health journey.

[Read more](#)

Brad Watson-Davelaar
@bwdphotocanada

Check out this feature by @GHLForg that I & other #IBD friends took part in for Crohn's & Colitis Awareness Week. It's been awesome taking part in these features & I truly hope it helps who comes across them. Some awesome people featured [#IBDVisible](#)

ghlf.org
8 Inflammatory Bowel Disease Patient Advocates Share Their Stories to Raise ...
This Crohn's and Colitis Awareness Week, advocates share their daily struggles with IBD — and how they've found support within the community.

11:45 AM · Dec 1, 2022

Natalie Hayden
@nataliesparacio

Kicking off Crohn's and Colitis Awareness week with this feature by @GHLForg that includes viewpoints and perspectives from #IBD patient advocates. Thanks for including me! [#crohns](#) [#colitis](#)

ghlf.org
8 Inflammatory Bowel Disease Patient Advocates Share Their Stories to Raise ...
This Crohn's and Colitis Awareness Week, advocates share their daily struggles with IBD — and how they've found support within the community.

8:52 AM · Dec 1, 2022

Podcasts

Building a More Just and Equitable Medicines System for All – with Priti Krishtel from I-MAK.

[The Health Advocates](#)

China Eases “Zero-COVID” Policy: Insight on the Implications.

[The Health Advocates](#)

Your Questions Answered: A Special Q&A Episode.

[Healthcare Matters](#)

EXTRA Part 2 – Non-Radiographic Axial Spondyloarthritis: A Conversation with Policy Expert Amanda Ledford and Patient Advocate Ricky White.

[The Health Advocates](#)

Health Policy and Advocacy Impact: A Look Back at 2022 and What’s Coming in 2023.

[The Health Advocates](#)

KEY LEGISLATION PASSED

Copay Accumulator Adjustors

[Delaware SB 267](#)

[Maine SP 621](#)

[New York S 5299A](#)

[Washington SB 5610](#)

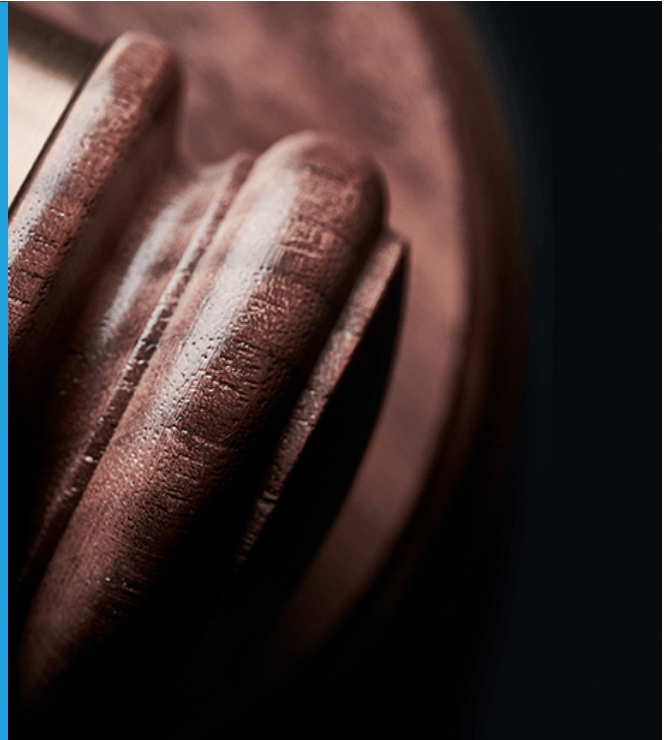
Non-Medical Switching

[New York S 4111A](#)

Step Therapy

[California AB1880](#)

[Massachusetts H4929](#)



LOOKING AHEAD

As we wrap up 2022, we’re looking forward to another year working to enact more patient-friendly legislation. 2023 is shaping up to be a big year for advocates to push back on insurance accumulator adjustor policies; already, it looks like there will be active legislation in **Florida, Texas, Pennsylvania, Colorado, Massachusetts, Michigan, Ohio, South Carolina, Utah, and Wisconsin**. Additionally, for Non-Medical Switching, we are currently looking at legislation in **Texas and Pennsylvania**. In **Washington** we are looking to pass a Pharmacy Benefit Manager (PBM) Reform bill. If you live in any of these states and want to raise your voice to support these laws, please reach out to us at advocacy@ghlf.org

CONTACT US

WEB:
www.ghlf.org

DIRECTOR:
Steven Newmark, JD, MPA
SNEWMARK@GHLF.ORG

ADDRESS:
515 N. Midland Avenue
Upper Nyack, NY 10960

**A D V O C A C Y & P O L I C Y
R E P O R T 2 0 2 2**

©2022 GLOBAL HEALTHY LIVING FOUNDATION

