




*“Making a Difference
from the Ground Up”*

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Today's Discussion

- 1) Speaker Background
- 2) Treatment Affordability
- 3) What's Going on in Washington?
- 4) The Importance of Becoming an Advocate



Who am I? What do I know about Advocacy?

Patient Advocate in College

Executive Assistance/Health LA for a
Member of Congress (4 Years)

Contract Lobbyist (2 years)

Director of Government Relations for a
patient assistance organization (17 years)

Built my own Nonprofit/Advocacy Firm (18
months)

What Role do Patient Assistance Programs Play?

Where do you turn:

- **High Cost of Health Insurance**
- **High Cost of Copayments**
- **Other Access Issues**

Patient Assistance Programs

- **Independent Charities**
- **Manufacturer Programs**
 - <https://liferaftgroup.org/financial-aid/>



Patient Assistance Programs for GIST Patients

Independent Charities

- **AccessiaHealth (Formerly PSI)**
- **Patient Advocate Foundation (closed)**



Accessia Health GIST Program

The Accessia Health Program Covers:

Copayment Assistance (Annual Maximum is \$8000)

Other Medical Expenses (Annual Max \$500)

Travel Expenses (Annual Max: \$300)

The AccessiaHealth Programs are currently at Capacity

They have a waitlist.

Check back to the website on the first of every month to see if the program opens up



ACCESSIAHEALTH GIST PROGRAM INFORMATION

Patient Programs | Accessia Health

- Apply Online

Federal Poverty Limit—475%

Type of Insurance—Public Insurance

Need to Provide:

- Demographic information
- Health insurance details
- Estimated household income and dependents
- Supporting Income Documentation
- Medical Statement to confirm the diagnosis

Patient Advocate Foundation

Metastatic Gastric Cancer

This Program is Closed

FPL is 400%

All Insurance Types can apply for assistance

Patient MUST reside and receive treatment in the United States

Funds help

- Co-payments
- Co-Insurance
- Deductibles
- Office visits and administration charges related to treatment
- Medical Insurance Premiums

Maximum Cap--\$4500.00



WHAT'S GOING ON IN WASHINGTON?

IT'S AN ELECTION YEAR

- ALL 435 MEMBERS OF CONGRESS ARE UP FOR ELECTION
- 1/3 OF THE SENATE
- 36 GUBERNATORIAL ELECTIONS
- TONS OF STATE LEGISLATIVE SEATS

IMPORTANT LEGISLATIVE INITIATIVES

- SAFE STEP ACT
- HR 5801, THE HELP COPAYS ACT

The Inflation Reduction Act

- Significant Changes in health care programs:
 - Enhanced Obamacare subsidies extended to 2025
 - HHS/CMS would be able to have limited negotiation abilities with manufacturers over drug pricing
 - Medicare Part D Plan Monthly Cap for Beneficiaries
 - Expanding Eligibility for low-income subsidies under Part D of the Medicare Program—Beginning January 1, 2024, raising the level of qualification from 135% to 150% of the federal poverty level
 - Improves access to adult vaccines under Medicaid and CHIP, prohibits cost sharing
 - Coverage of Adult Vaccines Recommended by the Advisory Committee on Immunization Practices under Medicare part D.
- BUT WILL IT PASS????



Congressional Appropriations Bills

House Labor/HHS/Education Appropriations Bill	\$10.5 Billion for the CDC, an increase of \$2billion over FY 2022		
	\$47 Billion for NIH an increase of \$2.5 billion over FY 2022	\$6.9 billion for the National Cancer Institute, \$466 million over FY2022	\$216 million for the Cancer Moonshot
	\$2.75 Billion for ARPA-H an increase of \$1.75 billion over the FY 2022		
Senate Labor/HHS/Education Appropriations Bill	\$10.5 billion for the CDC, an increase of \$2 billion over FY 2022 (Same as House)		
	\$47 Billion for the National Institutes of Health an increase of \$2.5 billion for FY 2022	\$7.2 billion for the National Cancer Institute, \$500 million over FY 2022	\$216 million for the Cancer Moonshot
	\$1 Billion for ARPA-H, level funded		



*In this country it is not
only permissible
to question our leaders
it's our responsibility!*

Michael J Fox, *The American
President*



**What do
you need to
become a
Great
Advocate?**

A Big Mouth

A Clear Message

No Shame

Ways to Promote GIST Awareness

WHO DO YOU KNOW?

Work with your government relations to recognize GIST Awareness Day/Week/Year

- Proclamations
- Resolutions

Know your Elected Official—make sure they know you

- Start with State Representative
- State Senator
- Members of Congress
- Senators



Building An Advocate



9/3/20XX

Presentation Title



Thank you

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