“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 your 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 Accessia Health 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.
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
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 $2 billion 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 FY 2022
- **$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
Thank you

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