

American Liver Foundation

NYC Hepatitis B Coalition
Meeting
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Yoshiaki Otake, MPH
Manager, Support Services



American Liver Foundation

Our mission is to facilitate, advocate,
and promote education, support, and
research for the prevention, treatment
and cure of liver disease.



Structure (cont.)

- 16 Divisions
 - Allegheny
 - Connecticut
 - Desert Southwest
 - Great Lakes
 - Greater Los Angeles
 - **Greater New York**
 - Heartland
 - Mid-Atlantic
 - Mid-America
 - Mid-South Nashville
 - Mid-South Memphis
 - New England
 - Northern California
 - Pacific Coast
 - Rocky Mountain
 - Upper Mid-West



National HelpLine 1-800-GO-LIVER

- ALF support services for individuals affected by liver disease and viral hepatitis
 - Patients
 - Family members, caregivers and friends
 - Health and social service providers
- National office in NYC
- HelpLine requests
 - Calls
 - Emails (ALF website & info@liverfoundation.org)
 - Letters
- Operation: 9am – 7pm EST Mondays-Fridays
- Currently staffed with 3 fulltime HelpLine Specialists
- Interpretation service in 20 languages upon request



National HelpLine 1-800-GO-LIVER

- Information frequently provided by HelpLine:
 - Viral hepatitis (ABC)
 - Financial assistance resources
 - Cirrhosis
 - Liver transplants
 - Healthcare providers
 - NAFLD/NASH
 - Alcohol-related liver disease
 - Liver cancer



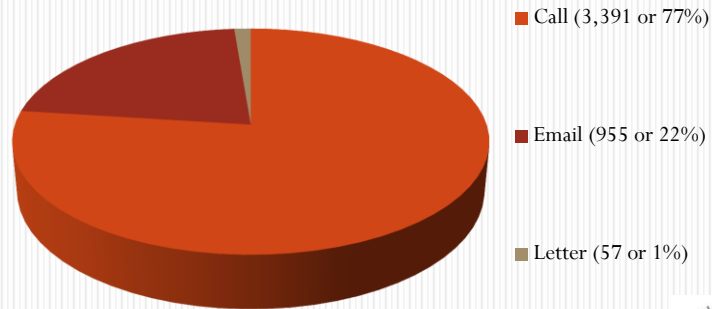
National HelpLine 1-800-GO-LIVER

- Many calls are anonymous
- States HelpLine serves most frequently
 - CA, FL, NY, TX, & NJ
- Top 5 most common liver diseases that callers are affected by:
 1. HCV
 2. NAFLD/NASH
 3. Liver Cancer
 4. Alcohol-related Liver Disease
 5. HBV



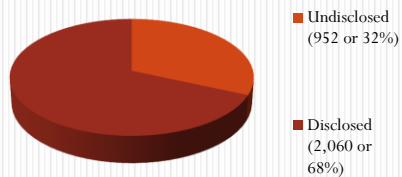
National HelpLine 1-800-GO-LIVER

FY2013 HelpLine (4,403)
Sources of contact

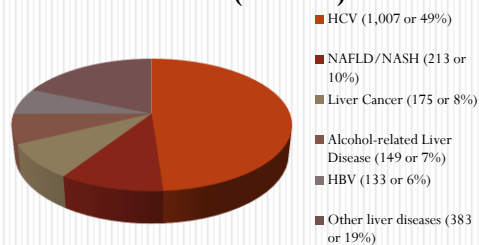


National HelpLine 1-800-GO-LIVER

Callers' liver disease



Callers' liver disease (disclosed)



National HelpLine 1-800-GO-LIVER

- Informal referrals to other resources
 - 1,400 informal referrals in FY 2013
 - Pharmaceutical's patient assistance programs
 - Copay assistance organizations
 - Local community health centers/FQHCs
 - Local specialists (gastroenterologists, hepatologists & infectious disease specialists)



National HelpLine 1-800-GO-LIVER

ALF healthcare provider locator

- Thousands of contact of physicians and facility
- Physician information from the Center for Medicaid and Medicare Services (CMS) & American College of Gastroenterology (ACG)
- FQHC information from the Health Resources and Human Services (HRSA)
- Substance abuse/drug treatment center information from the Substance Abuse and Mental Health Services Administration (SAMHSA)



National HelpLine 1-800-GO-LIVER

- HelpLine will NOT be able to:
 - Provide medical advice or recommendations
 - Interpret lab tests for patients
 - Recommend specific healthcare providers and facilities
 - Provide individual patient advocacy or case management
 - Provide direct crisis interventions
 - Refer to appropriate emergency contact
 - County emergency department
 - National Suicide Prevention LifeLine: 1-800-273-8255



American Liver Foundation Online Support Community



- Patient community hosted by Inspire www.inspire.com/groups/american-liver-foundation/
- Peer-to-peer support & information exchange
- Patients and family members affected by various liver disease
- Currently approximately 4,500 members
- Alternative for those with no access to in-person support groups or those with rare disease

