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www.hcvadvocate.org

www.hbvadvocate.org

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Overview and Objectives



- My Story: One person's story
- Making a difference
 - Provide examples of different forms of advocacy
 - How YOU can make a difference
 - Provide concrete examples to take action



- Diagnosed in 1996
 - Treated 3 times
 - Last treatment with pegylated interferon and ribavirin for 70 weeks – viral cure
- Member of Hepatitis Community Advisory Board
 - Meet with pharmaceutical companies for clinical study development
- Member of a Data Monitoring Safety Group – 5 studies



My Story

Early Years

- Grew up in the San Francisco Bay Area – teenage years during the 1960's—we were very poor
- Many operations = self advocacy education
- 30 years old – clean and sober



Changes:

- Back to school and job training
- Became a bookkeeper / accountant
- Worked in accounting for 20 years
- Various health issues –
 - Kidney
 - Neck & back

Volunteer Work

- Volunteered with HIV Service Organizations
 - Hospice
 - One-on-one peer support

Making a Difference

- **Soul Searching**
 - What kind of impact does an accountant have in the big picture? To me – zero, zilch, nada!
 - What did I want to do to help people?

Next Steps

- Occupational testing
 - Journalism, counselor, health care industry
 - Educator (teacher)

- Back to School

HCV Diagnosis



- **Diagnosed in 1996**
 - **Symptoms for at least 2 years**
- **First treatment:**
 - **Only 9% chance of success – I needed more education**
 - **Also needed some peer support**
 - **Pledge to start a support group**



Hepatitis C Support Project

Educational Materials



- HCV Information Packet



- Now - ~ 15 pieces

– 2011 = 600,000 pieces produced and distributed

Support Groups

- Started 1997
- HCV monoinfection
- HIV/HCV coinfection*

* Took course AIDS Health Project for HIV/HCV group

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Launched in 1998

Provide education for patients and
service & healthcare providers

Launched: 1,000 hits/week
2011: 500,000 hits/week

Education & Training



National Training Program

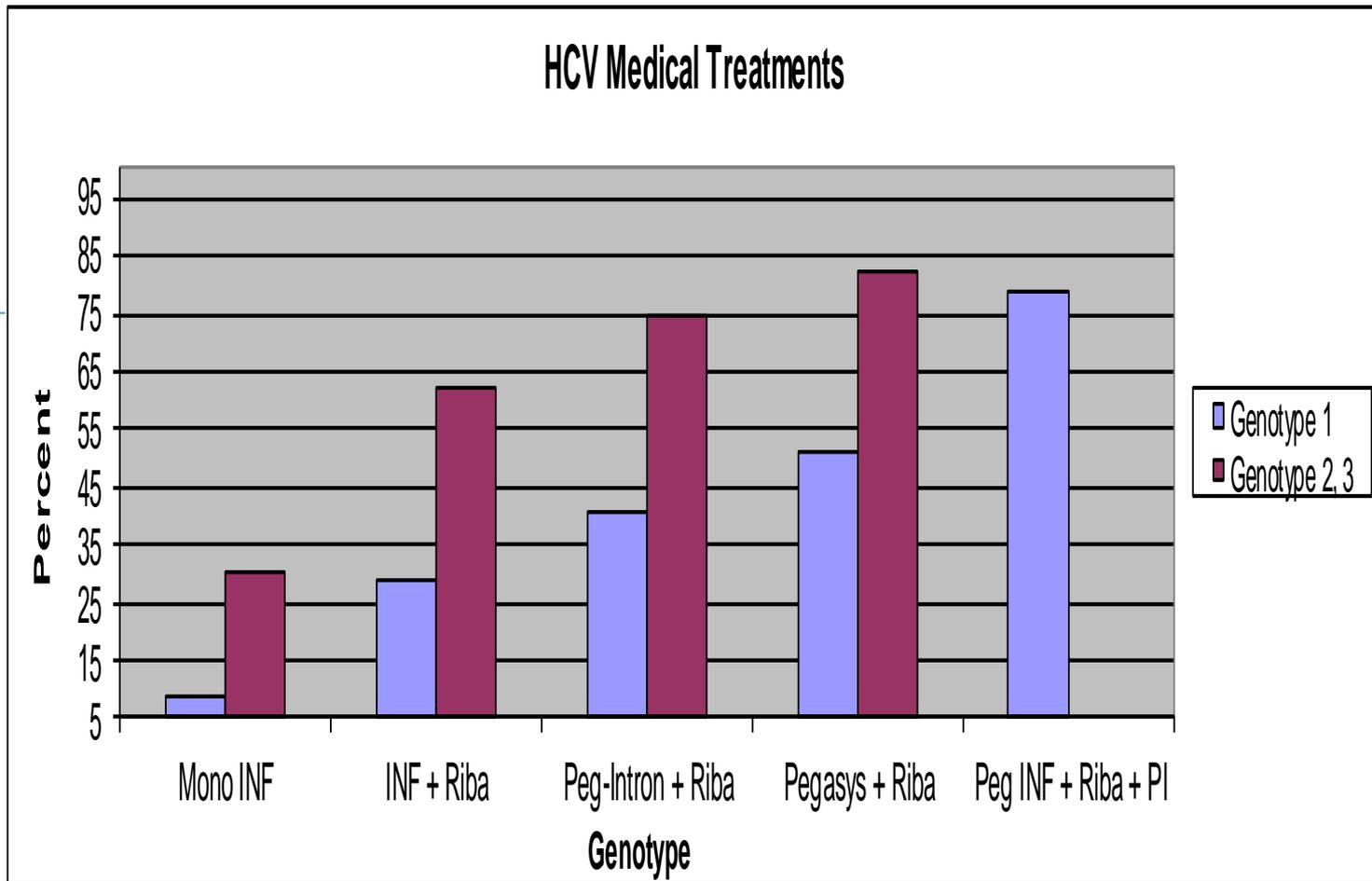
- Launched in 2002
- Conducted trainings in every state and in Canada and Mexico

- Every person affects 50 people
- 10,000 people have attended =
500,000 / YR

What I Learned

- Passion
 - Collaborate
 - Don't duplicate
 - Devote time & energy
 - Stick with it
 - Resolve issues
 - Common sense
 - Think & speak in client language
 - Learn as you go
 - Open mind
 - Attention to detail
-
- Surrounded myself with talented & passionate people
 - Turned negatives into positives

We Need Help!



Interferon-free by 2015 – Phase II up to 99%

WE NEED YOUR HELP!

Where's the Money?

National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Prevention Funding

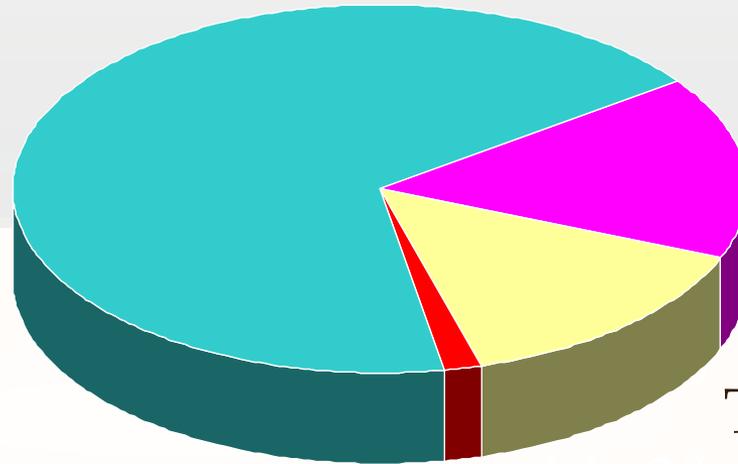
\$1 Billion Total

Domestic HIV
69%

STD 15%

TB 14%

Hepatitis 2%



Source: CDC

Why We Need Your Help:



- One Adult Viral Hepatitis Coordinator per state and in certain cities
- Very few services
- Low knowledge base among medical and service providers

Help!



- Little or no case management
- Large portion of HCV population is uninsured or underinsured
- Not enough medical providers to identify, manage and treat HCV population
- Few support services for HCV population

Questions---



- What's your passion?
- How much time can you devote?
- What is realistic for you?
- Are there any groups or organizations you can work with?
- What do you want to get out of advocacy?
- What would you like to accomplish?

What You Can Do:



Research



Client Needs

Advocate



For Clients

Education



- Educate Yourself
- Educate others – pledge to talk with 10 people about hepatitis C – have them pledge to tell 10 others

Volunteer



- Work with groups who have a known high prevalence of HCV
 - Injection drug users
 - People who are HIV/HCV Coinfected
 - Homeless groups and people
 - Veterans especially Vietnam Veterans
 - Prisoners and prison groups

Presentations - Information



- Church
- Health fairs
- Civic organizations
- Booths at local events

Internet & Social Media



- Google or Yahoo Groups
- Blogs
- Start or join existing
 - Twitter
 - Facebook- groups

News



- Develop a simple newsletter - 1 or 2 page to distribute within agency or group
- Compile news articles

One of the single most important services you could provide

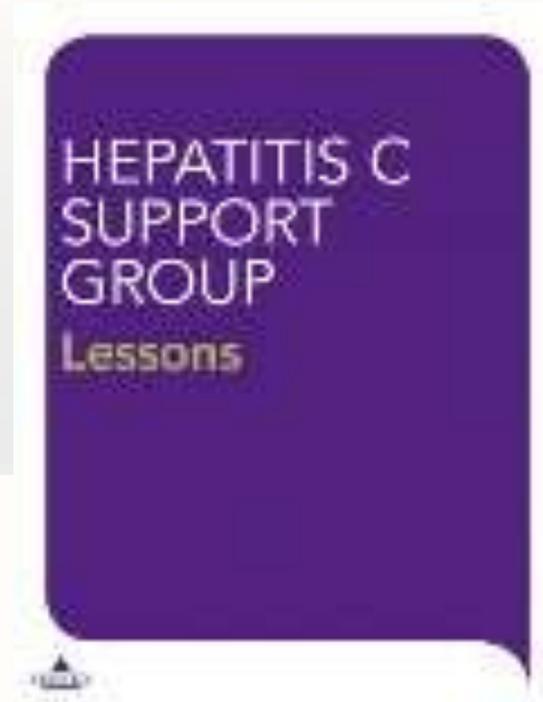
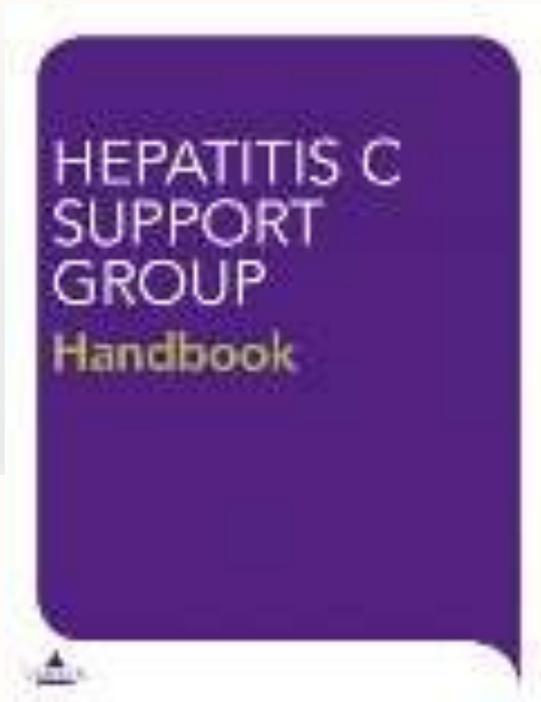


Support Groups

- Newly diagnosed
- Coping with a chronic illness
- Treatment issues
- Clients, Family, etc.

- Informational
- Emotional

Support Group Manual & Lessons



Educational Materials



- Develop simple fact sheets that are tailored to meet your clients' needs
- Keep messages consistent
- Develop informational packets
 - Education, Newly Diagnosed packets
 - Services

Examples:



EASY C FACTS

What is Hepatitis C?

Hepatitis C (HCV for short) is a virus that lives in human blood. A virus is one of the smallest living things known to exist inside plants and animals. HCV makes new hepatitis C viruses by infecting the liver, and after many years the liver can become so damaged by hepatitis C that it cannot perform many of the important jobs that it must do to keep us healthy.

You can only get hepatitis C by getting HCV infected blood from someone who has hepatitis C, and ONLY if that infected blood gets into your body. If you have hepatitis C you should make sure that your blood does not come into contact with someone else's blood.

Remember.....

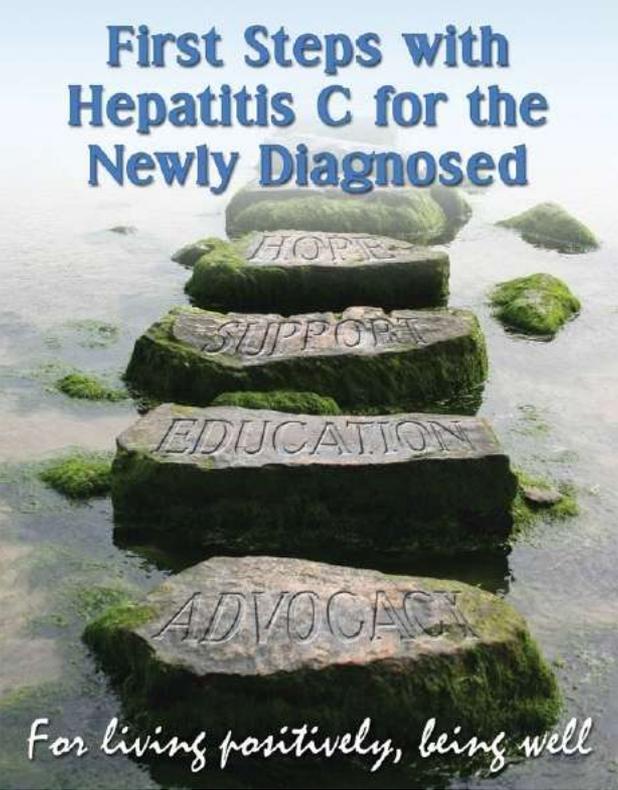
- ♦ Many people have hepatitis C so you are not alone. It takes many years for hepatitis C to cause damage to the liver and to make someone sick.
- ♦ There are many things that people can do to help fight hepatitis C, and the best time to start is early – before hepatitis C has a chance to damage your liver.
- ♦ One of the most important things you can do is to stop or cut down on drinking alcohol.
- ♦ There are also medicines to get rid of hepatitis C that work in about 8 out of 10 people treated.
- ♦ Talk with your doctor about ways to stay healthy and about the medications that can cure hepatitis C, and if they can help you.

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 HEPATITIS C SUPPORT PROJECT 06/2012

by Alai Francisco

First Steps with Hepatitis C for the Newly Diagnosed



HOPE
SUPPORT
EDUCATION
ADVOCACY

For living positively, being well

Distribute Educational Materials



- Make sure agency is stocked with materials about hepatitis C

Examples:

- HCV Advocate, State Health Department, CDC, American Liver Foundation

Health Departments & Task Forces



- Adult Viral Hepatitis Coordinator
 - Texas: Larry Cuellar
- Collaborate with local & state health departments
- Hepatitis C CBOs
- Task Force – City/County/State



Media Advocacy



- Develop a Media Kit –
 - Standardize form
 - Simple fact sheet
 - Glossary
 - Contacts
- Develop relationship with reporters – my experience
- Write editorials to local papers

Political Advocacy



- Challenge local, state and national politicians
- Meet with your local, state and national politicians
- Volunteer for political candidates

One person can make a difference That.....



- One piece of educational material
- Support group
- Media contact
- Politician
- Collaboration
- Vote

...Can make a huge difference in someone's life



VOTE

This is a critical election

Health Care Issues

Women Issues

Immigration Issues

LGBT Issues



Thank You

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