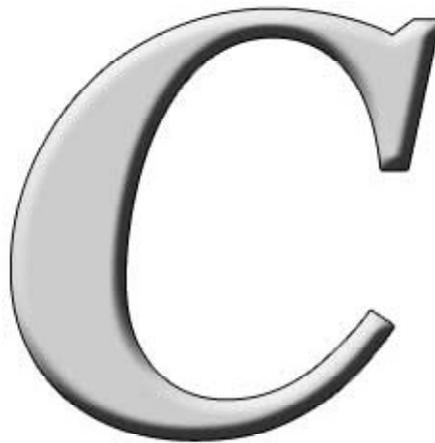


*Santa Barbara*

*County*

*Hepatitis*

*Strategic Plan*



# Santa Barbara County Hepatitis C Task Force

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## Acknowledgements

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The Santa Barbara County Hepatitis C Task Force came together in the spring of 2001 to develop a comprehensive Hepatitis C Strategic Plan for Santa Barbara County. Modeled after the Strategic Plan developed by the State of California, a multi-disciplinary group of individuals convened a year-long process to adapt the state model to one that is community based and appropriate for the Santa Barbara region.

Inspired by Kathie Lustig, the director of “Back to Life” Hepatitis C Education, Prevention & Support Project, the task force started its journey by soliciting support and participation from a diverse group of health professionals, individuals of the infected and affected community, county agencies, representatives from pharmaceutical companies and community based organizations. These individuals gave countless hours to develop the ideas and recommendations that make up the Plan. Kathie Lustig provided her extensive expertise as director and coordinator of hepatitis C support groups and educational programs, patient advocacy and participation in the planning and development process of the State Hepatitis C Strategic Plan.

A special thanks goes to Carol Craig, consultant and facilitator. Carol was a driving force in the development of the State Plan and skillfully guided the Santa Barbara County Hepatitis C Task Force through the process. Carol, Director and Patient Advocate of the California Hepatitis C Resource Center in Orange County and Clinical Research Coordinator, University of California, Irvine has eight years of experience working with individuals with hepatitis C.

Significant contributions were made to the developmental process by the Santa Barbara Public Health Department for providing a meeting space and supporting the process financially and with their expertise in HIV/AIDS, communicable disease control, medical social work, and health education. Frank Alvarez, M.D., Deputy Health Officer and his staff provided the group with the pulse and leadership to move forward with a community plan in the face of challenges to the prevention and treatment of this widespread disease. Dr. Alvarez and staff brought extensive communicable disease and epidemiological expertise to the forum. Jayne Brechwald, MPH, Director of Health Promotion, contributed health education and editing expertise, and brought the perspectives gained from her appointment as part of the State Strategic Plan efforts to the Task Force.

Other participating physicians include Robert Gish, M.D., Medical Director, Liver Disease and Transplant Program, California Pacific Medical Center who authored portions on the section of disease management, Howard Zisser, former Lompoc Community Clinic Physician and Director, Clinical Research, Sansum Medical Research Institute. Dr. Maurizio Bonacini, Hepatologist, California Pacific Medical Center, and Patricia Perkins, MA, MPH, Director, RHORC Interior Bay Area San Francisco State University, Dept of Health Education graciously provided extensive medical review of the Strategic Plan.



Special thanks to Tomas Aragon, MD, Dr PH, Community Health Epidemiology & Disease Control, San Francisco Department of Public Health and Luther Brock, Program Director of AIDS Community Resource Consortium (ACRC) in San Mateo County for taking the time to travel to Santa Barbara and present their valuable input to the Task Force.

Other public entities and community-based organizations gave valuable input and time based on their direct service experience. Rafael Cosio, Pacific Pride Foundation, Dennis Feeley, Santa Barbara Neighborhood Clinics, St. Francis Medical Center Parish Nursing, Tri-Counties Blood Bank, Santa Barbara Regional Health Authority, AIDS Housing Santa Barbara, Project Recovery (CADA), Santa Barbara County Alcohol, Drug and Mental Health, and "Back to Life" Hepatitis C Education, Prevention & Support Project, a Tides Center Project. Each of these agencies brought passion for the project and expertise to each meeting in the areas of substance abuse, HIV/AIDS, hepatitis C support and education and working with populations who are underserved. Collectively, these people have helped to improve the lives of individuals already affected by hepatitis C and have helped reduce the spread of new infections.

#### **Strategic Plan Consultant and Facilitator**

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#### **Financial Support**

A special thanks to the **Fund for Santa Barbara** for recognizing the need to address hepatitis C issues and providing the seed money to "Back to Life" to begin this process of the Santa Barbara Hepatitis C Task Force. The **Santa Barbara Foundation** saw the value in providing additional monies to convene additional meetings, complete the plan and begin the dissemination process. The **Santa Barbara Public Health Department** provided staff hours, meeting space, and consultant facilitator fees. **Fujisawa and Roche Pharmaceuticals** provided their expertise on hepatitis C and donated lunch and refreshments. **Roche Pharmaceutical** and the **Santa Barbara Public Health Department** also provided funds for the printing of the Strategic Plan. Most recently, **The California Endowment** has provided "Back to Life" a significant grant to further disseminate the Strategic Plan. The "Back to Life" Hepatitis C Education, Prevention & Support Project will coordinate key community stakeholders and ensure delivery of HCV primary and secondary prevention in Santa Barbara County. "Back to Life" will also develop and distribute a HCV Resource Guide and develop a Task Force web site ([www.SBHCVtaskforce.org](http://www.SBHCVtaskforce.org)-scheduled for completion Summer 2003) where providers can download the plan, as well as access important updates and valuable information to assist them in providing hepatitis C services.

#### **The contributing authors**

Frank Alvarez, M.D. and epidemiological staff, Robert Gish, M.D., Kathie Lustig, Carol Craig, Jayne Brechwald, MPH and Patricia Perkins, MA, MPH. Excerpts regarding an Overview of Hepatitis C were taken from the California Dept. Health Services Hepatitis C Strategic Plan 2001, Centers for Disease Control (CDC) National Hepatitis C Prevention Strategy 2001, National Institutes of Health Consensus Development Conference Statement 2002.



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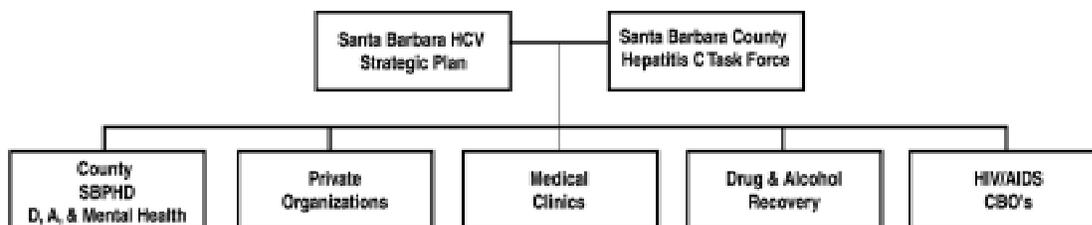
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## About the Task Force/Purpose of the Strategic Plan

The Santa Barbara Hepatitis C Strategic Plan (SBHCVSP) was developed for use by the county, private organizations, medical clinics, drug and alcohol treatment providers, HIV/AIDS organizations and community based organizations who are or will provide care and services for those infected or affected by hepatitis C. The Strategic Plan is a tool to plan services and obtain funding for these under-funded and under-addressed healthcare needs. The outcomes of this planning process are fourfold:



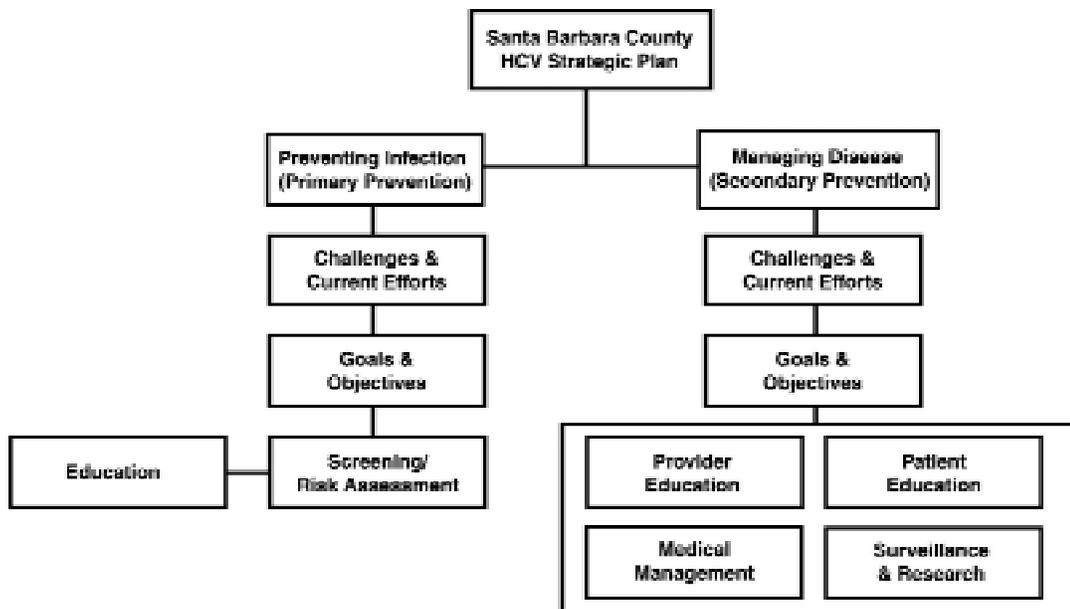
- ◆ *To Prevent New Infections*
- ◆ *Identify Those Who May Have the Disease*
- ◆ *Provide At-Risk Individuals With Access to Testing*
- ◆ *To Medically Manage the Chronically Infected*



### Strategic Plan Development

There is a large pool of undiagnosed people infected with hepatitis C that will burden our healthcare and social service community in the years to come. This plan came about by the desire of the Task Force to improve services to hepatitis C patients, their families and caretakers. This Plan will aid providers in planning for the significant impact hepatitis C will have on their organizations in the future.

Within each component area are sub-components, definitions are provided, current efforts and challenges are outlined, and objectives for each sub-component are identified. These objectives are in order of priority as determined by the Santa Barbara Hepatitis C Task Force. Throughout the plan you will see the component headings “Preventing Infection and Managing Disease” are provided along side the classic public health terminology “Primary and Secondary Infection”. The members decided to use these terms as component names to ensure the plan could be easily understood by laypersons.



Components of the Strategic Plan

*Preventing Infection (Primary Prevention)*

- ◆ Screening

*Managing Disease (Secondary Prevention)*

- ◆ Provider Education
- ◆ Patient Education
- ◆ Surveillance & Research
- ◆ Medical Management

For definitions of terms that are used throughout the plan, including various medical terms, please refer to the Glossary at the back of the plan. Local, state and national resources are also listed in the back of the plan, as well as links to excerpted documents.

Also in the back of this document, you will find a survey we hope you will take the time to fill out. It will also be posted on-line for your convenience at the web site below. Your comments will aid in future planning including providing information on how we can help your organization, and to help assess the plan's usefulness to the community. Please let us know if you would like more information on how the Plan can help your organization, and/or if you would like to be listed in the future Hepatitis C Resource Directory.

On behalf of the Santa Barbara Hepatitis C Task Force, we hope you find this document useful. We encourage you to make any comments or suggestions by sending an email to [klustig@cox.net](mailto:klustig@cox.net). This plan will be posted in its entirety, along with other useful information at [www.sbhcvtaskforce.org](http://www.sbhcvtaskforce.org).

## Mission Statement

The purpose of the Santa Barbara County Hepatitis C Strategic Plan is to outline a community collaborative, coordinated, comprehensive, culturally appropriate, and systematic approach that will prevent the spread of hepatitis C infection in Santa Barbara County, limit the progression and complications of hepatitis C-related liver disease, and advocate for hepatitis C prevention, education, support, and treatment policies and resources.



## Vision Statement

The vision is a coordinated countywide effort supported by public and private partnerships to provide comprehensive services that assure:

- Accessible hepatitis C counseling, screening, education, treatment, harm reduction and prevention efforts;
- Education of providers, policymakers, and the community about hepatitis C;
- On-going assessment of community needs by collection and analysis of hepatitis C data;
- Foster and support of hepatitis C related research in Santa Barbara County
- Reduction in the number of new hepatitis C infections and related deaths in Santa Barbara County.



## Overview of Hepatitis C

[Excerpted from Calif. Dept. Health Services Hepatitis C Strategic Plan 2001, National Institutes of Health Consensus Development Conference Statement 2002, Centers for Disease Control (CDC) National Hepatitis C Prevention Strategy 2001]

### What is hepatitis C?

*The hepatitis C virus (HCV) is the most common chronic bloodborne viral infection in the United States and is the leading cause of known liver disease. It is the most common cause of cirrhosis and a common cause of hepatocellular carcinoma (HCC); it is also the most common reason for the need for liver transplantation. The hepatitis C virus enters the body through direct blood exposure. Following the identification of hepatitis A and hepatitis B, this disorder was categorized in 1974 as “non-A, non-B hepatitis.” In 1989, the hepatitis C virus was discovered and was found to account for the majority of those patients with non-A, non-B hepatitis. It is estimated to have infected as many as 242,00 Americans annually during the 1980’s. Since 1989, the annual number of new infections has declined by more than 80 percent to approximately 41,000 by 1998. A national survey (the third National Health and Nutrition Examination Survey (NHANES III) of the civilian, non-institutionalized U.S. population found that 1.8 percent of Americans (3.9 million) have been infected with HCV, of whom most (2.7 million) are chronically infected with HCV. These estimates of prevalence are likely conservative, because the survey excluded incarcerated and homeless persons, groups that have high prevalence of HCV infection. Most infected persons were aged 30-49 years when the survey was done in the early 1990’s.*

*Based upon national data, an estimated 600,000 Californians are currently infected with hepatitis C. Additionally, it is estimated that in California, 5,000 people are newly infected each year.*



*Most people with hepatitis C are chronically infected; unaware they carry the virus, but may have no or only mild symptoms (loss of appetite, malaise, muscle and body aches, or abdominal pain). For this reason, many have not sought diagnosis and treatment. Nonetheless, the disease may be progressively harming the liver and infected persons may transmit the disease to others unknowingly. The consequences of chronic liver disease from hepatitis C do not become apparent until 10 to 20 years after infection.*

*The early period after exposure is referred to as “acute” hepatitis C infection. After acute infection, the immune system in about 15-25% of infected people appears to clear the virus and resolve their infection. In selected cohorts ( Irish/ German), as many as 45% of women cleared the HCV RNA spontaneously. However, most people develop chronic hepatitis C infection. At present, it can be difficult to distinguish between acute, chronic or resolved infection, based on laboratory testing.*

*As the hepatitis C infection progresses slowly over the years, about 20-25% of infected people will develop advanced liver disease in their lifetime, and between 1% to 5% will die from liver cancer. The remaining hepatitis C-positive people appear to function without major health problems.*

*Already, hepatitis C is the leading cause of chronic liver disease and of liver transplants in the United States. It is estimated that the number of cases needing liver transplants will grow and thereby strain an already limited supply of donated livers. Hepatitis C is responsible for 8,000 to 10,000 deaths per year nationwide; the annual costs of acute and chronic hepatitis C exceeds \$600 million. Using these federal figures, estimates for hepatitis C in California would add more than \$50 million to health care costs per year. Persons with hepatitis C-induced chronic liver disease are also at greater risk for severe disease due to hepatitis A and B.*

*About 1,000–1,200 Californians per year die from hepatitis C infection; this number is expected to increase four-fold over the next 20 years.*

Santa Barbara County - Using the CDC's overall estimate that approximately 1.8% of a general population is infected with the Hepatitis C virus, we can estimate that there are approximately 6,400 individuals in Santa Barbara County that are currently infected with the virus. Using the same percentage of county residents that the State used to obtain their estimate, an average of 12-14 individuals expire in Santa Barbara County each year due to Hepatitis C.

## What are the Risk Factors for Hepatitis C

HCV transmission occurs primarily through exposure to infected blood through direct percutaneous exposure. This exposure exists in the context of injection drug use (IDU), blood transfusion, solid organ transplantation from infected donors, unsafe medical practices, occupational exposure to infected blood, birth to infected mothers, multiple heterosexual partners, and high-risk sexual practices. High HCV seroprevalence rates (from 15 to 50 percent) have been observed in specific subpopulations, such as homeless, incarcerated persons, and hemophiliacs, with the highest rates (70 percent to more than 90 percent) reported in IDU's. For homosexuals the rate is as high as 10% in some cohorts, with an average of 4-8% in MSM (men having sex with men).





Individuals who injected drugs, even if they did so on only one occasion many years ago, are at highest risk for HCV infection. HCV infection is rapidly acquired following the initiation of injection drug use and occurs from the sharing of needles, syringes, and other equipment associated with drug use and it accounts for over two-thirds of all new infections. Needle and syringe exchange programs and comprehensive risk-modifying education programs that are highly effective in preventing HIV transmission are likely to be useful for decreasing HCV transmission.

Prior to the mid-1980's there was a 7 percent to 10 percent risk of non-A, non-B hepatitis (hepatitis C) from a blood transfusion. This risk declined by more than 50 percent between 1985 and 1990 as a result of implementation of blood donor screening for HIV and surrogate testing for non-A, non-B hepatitis. In 1990, specific donor screening for HCV was implemented and by 1992 the risk of HCV infection from a unit of transfused blood was reduced to one in 100,000. As of 2001, the risk of HCV infection from a unit of transfused blood is less than one per million transfused units.

Clotting factor concentrates, which are plasma derived products used to treat individuals with hemophilia, posed a high risk for HCV prior to the use of virus inactivation procedures that were introduced in 1985 and 1987. Except for one outbreak of hepatitis C from a single type of contaminated intravenous immunoglobulin, other plasma-derived products, including immune globulin for intramuscular administration, have not been associated with the transmission of HCV in the United States. Currently, all immune globulin products undergo a virus inactivation procedure or test negative for HCV prior to release.

The majority of other cases can be attributed to sexual transmission and occupational exposures to blood, although the actual risk of transmission through these routes is low. Data regarding transmissibility by sexual contact has been confounded in part by other exposures, including IDU that can increase the risk of transmission.

In the United States, the estimated seroprevalence of HCV is 2 to 3 percent among partners of HCV-infected persons who are in long term monogamous relationships and is 4 to 6 percent among persons with multiple sex partners, sex workers, and men who have sex with men (those at risk for sexually transmitted diseases) For heterosexual, discordant monogamous couples, the risk of transmission is estimated to be 0 to 0.6 percent annually, with the risk to females being threefold greater than to male partners. Because of the low risk of HCV transmission, couples need not use barrier protection (condoms); however, couples should be advised that the use of condoms may decrease the risk of HCV transmission. Based on studies in persons at risk for sexually transmitted disease, HCV transmission is approximately 1 percent annually. HCV-infected individuals with multiple sexual partners or in short-term relationships should be advised to use condoms to prevent transmission of HCV and other sexually transmitted diseases.

The sharing of common household items, such as razors and toothbrushes, is another potential source of transmission of HCV. There is no evidence that kissing, hugging, sneezing, coughing, food, water, sharing eating utensils or drinking glasses, casual contact, or other contact without exposure to blood is associated with HCV transmission.

The risk of HCV infection from needle stick is estimated to be 2 percent. Healthcare workers may have a slightly higher prevalence of HCV infection than the general population, although they may have acquired infection from nonoccupational sources. Transmission from healthcare workers to patients has also been documented, but is rare and is confounded by other risk factors.

Percutaneous exposures, such as body piercing and tattooing, are other potential sources of transmission if contaminated equipment or supplies are used. However, the rates of transmission are less than 1 percent, and these data are confounded by other risk factors.

The risk of hepatitis C transmission from mothers to infants and among non-sexual household member's exposure is low. Higher maternal HCV RNA load appears to be associated with greater risk for HCV transmission to the infant. The risk of transmission is approximately 2 percent for infants when the mother is HCV seropositive. HCV transmission may be increased to approximately 10 percent with maternal injection drug use and up to 20 percent in women co-infected with HCV and HIV. There are no prospective studies evaluating the use of elective Cesarean or non-use of internal fetal heart monitors used in child birth for the prevention of mother-to-infant transmission of HCV. There are currently no data to determine if antiviral therapy reduces perinatal transmission. Ribavirins and interferons are contraindicated during pregnancy.



Breastfeeding does not appear to transmit HCV. Children and personnel should not be excluded from daycare because of hepatitis C infection. Standard universal precautions should be used in any situation where blood or blood products are used.

## Reporting of Hepatitis C

Although health care providers in California are required to report all cases of hepatitis C to the local health department, it is vastly under-reported, which makes it difficult to estimate how widespread the disease really is. Reasons for under-reporting include differences in definitions for acute and chronic infections, lack of testing, interpretation of laboratory tests, and confusion over reporting requirements. These problems are limiting factors in having accurate and current surveillance data with which to identify the number of infected persons, the number at risk of becoming infected, and the extent of the problem in California.

## Who Gets Hepatitis C?

[Excerpted from Calif. Dept. Health Services Hepatitis C Strategic Plan 2001, Santa Barbara Public Health Dept.]

*Hepatitis C infection occurs at all ages. Nationally, it is found most frequently among persons aged 30-49 years, and is slightly more common among males than females and among African Americans than whites. Since 1996, when hepatitis C first became reportable in California, through 1999, approximately 76,430 cases have been reported. Of the 76,430 cases reported, 64% were male and 35% female. All age groups were represented, but 91% were between 20 and 64 years old with a median age of 43.*

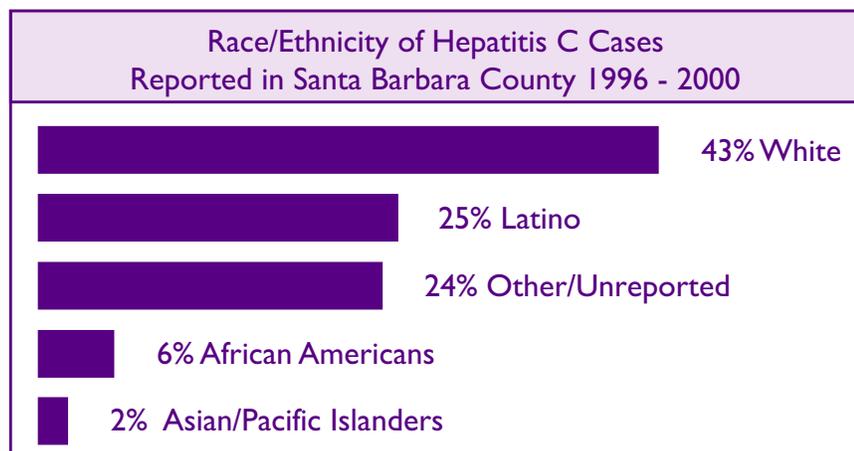
*Santa Barbara County - Combining the estimates of the numbers of infected by age categories with estimates obtained from the Centers for Disease Control and Prevention's National Health and Nutrition Examination Survey (NHANES) III and the California State Department of Finance's County Population Projections with Age, Sex, Race/Ethnicity for July 1990-2040, we derive the following estimates for our county broken down by age:*

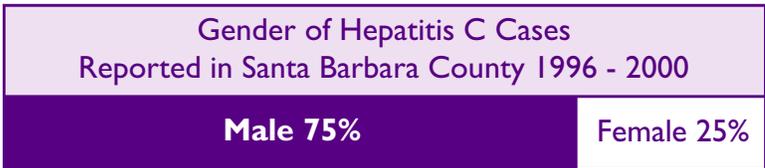
Age (years)	HCV infected
5-19	272
20-29	866
30-39	2633
40-49	1866
50-59	583
60-69	239
70-79	217
80+	265

NHANES III also found that nationally, 2.5% of males were infected compared to 1.2% of females, meaning approximately 5,220 males and 2,439 females in Santa Barbara County. Nationally, the infection was more often found amongst Blacks (3.2%) than Whites (1.5%), and those aged 30-39 had the highest infection counts (as also seen in the above estimates) and accounted for 65% of all cases. Modeling predicts that those persons born between 1940-1965 have the greatest lifetime risk of acquiring HCV. For those infected more than 10 years ago, about 30% each was attributable to IVDU and transfusions. For those infected within the last 10 years, IVDU accounts for 60% of cases. Race/Ethnicity of hepatitis C cases reported in California, 1996-1999 (N = 48,151): White 52%, Latino 28%, African American 12%, Asian/Pacific Islander 6%, Native American 1%, and Other 1%.

See the following two figures for gender and race/ethnicity breakdown of Hepatitis C cases reported in Santa Barbara County in 1996-2000 (note: these are convenience data not from a population-based survey and they are subject to screening and reporting biases).

When including all the reported Santa Barbara County HCV cases from 1996 through 2000 (N = 1,496), the rates of infection vary by race/ethnicity. The rates follow: 641 cases per 100,000 for Non-Hispanic Whites, 4,448 cases per 100,000 for Hispanics, 1,061 cases per 100,000 for Non-Hispanic Blacks and 4,244 cases per 100,000 for Asian/Pacific Islanders. The rates are derived from the California State Department of Finances' County Population Projections with Age, Sex, Race/Ethnicity for July 1990-2040 (note: these are convenience data not from a population-based survey and they are subject to screening and reporting biases).





## Additional Risk Group Information

The Santa Barbara County Alcohol and Drug Treatment Program (2001-2002) reported that 1850 individuals (in treatment) reported using a needle for drugs in the past year. HCV infection prevalence rates in this group average around 80% according to the CDC, leaving a conservative estimate (those not in treatment aren't quantified) of 1480 infected persons just within that high-risk sub-population.

We have an estimated 35,000-45,000 veterans residing in Santa Barbara County. A recent study found nearly 8% of 26,000 patients in Department of VA facilities tested positive for HCV. A six-week survey at the VA Medical Center in Washington, DC found 20% of inpatients tested positive for the virus. An investigation at the VA Medical Center in San Francisco found that 10% of inpatients tested positive. Utilizing 10% as the estimate of infection in our county's vet population approximately 3,500-4,500 are infected. Utilizing the more conservative estimate of 2%, 700-900 vets are infected with HCV in Santa Barbara County. (Source: Veterans Helping Veterans™ A comprehensive guide for Veterans infected with Hepatitis B and C; [www.geocities.com/hepvvet/HCV1.html](http://www.geocities.com/hepvvet/HCV1.html))

## Chronic Liver Disease/Long-term Care Costs

[Excerpted from Economics of Hepatitis C in the US, 2002, W.R. Kim, MD MBA, Mayo Clinic, and [www.epidemic.org/theFacts/theEpidemic/USHealthCareCosts.html](http://www.epidemic.org/theFacts/theEpidemic/USHealthCareCosts.html); 1998 Dartmouth College]

Approximately 80% of persons infected with HCV will develop chronic liver disease (~ 6,400 in Santa Barbara County-based on CDC national estimates of 1.8%) and of those as many as 25% may develop cirrhosis within 10-20 years (~1,600 in Santa Barbara County). Estimates of the proportion of chronically infected persons who develop cirrhosis 20 years after initial infection have been substantially higher from retrospective studies (17-55 percent) than from prospective studies (7-16 percent). The actual risk of progressive disease at 20 years is now considered to be closer to the estimates from prospective studies. Risk of liver cancer approaches or exceeds 1% per year after cirrhosis develops. (~80 in Santa Barbara County). It is estimated that 40-50% (~40 in Santa Barbara County) of those with cirrhosis will develop decompensated liver disease and require a transplant and/or will result in patient demise.

Estimated number of infected in Santa Barbara County	6,400
Estimated number that may develop cirrhosis	1,600
Estimated number with liver cancer	80
Estimated number needing transplant	40

A recently published study on the burden of gastrointestinal disease in the US was sponsored by the American Gastroenterological Association (AGA) and undertaken to estimate the prevalence and annual economic burden of common gastrointestinal (GI) disorders, including HCV, cirrhosis, and hepatocellular carcinoma. Data were obtained from publicly available national data sets and other proprietary databases. The total costs for each disease included estimates for both direct and indirect costs. It is estimated that approximately 2.5 million Americans (\*does not include some high risk groups) had HCV, which incurred \$693 million in healthcare services and \$51 million in direct costs in 1998.



Of the direct costs attributable to HCV, the largest proportion was from outpatient activities. It was estimated that some 317,000 physician office visits for HCV incurred \$23.9 million in physician services. In addition, there were 46,000 visits to hospital outpatient departments (including emergency department) with total costs of \$10.5 million. Pharmaceuticals were the single largest item in costs related to hepatitis C. The reported sales of combination of interferon alfa-2b, peg-interferon and ribavirin for the year 2002 in the U.S. was \$1.9 billion.

With regards to hospital care costs, the AGA study estimated that there were 61,000 inpatient stays related to hepatitis C, 91% of which were secondary diagnosis of hepatitis C. These hospitalizations generated \$20.7 million in physician fees and \$107.9 million in facility costs, for a total of \$128.6 million. In another study based on 1995 data, there were 26,700 hospitalizations and 2,600 deaths in acute, nonfederal hospitals in the US for liver disease caused by HCV. Total charges for these hospitalizations were \$514 million. The two studies are not directly comparable because of a number of differences in methods. Thus, the true inpatient costs for hepatitis C-related liver disease may lie somewhere in between the two studies.

Based on the AGA estimates, the combined total costs attributable to hepatitis C is at least \$744 million. Thus, the total cost per person infected with hepatitis C (\$744 million/2.5 million persons) is \$294, including \$274 in direct costs and \$20 in indirect costs. Again, these likely represent underestimation of the true economic burden. However, it does point out that it is only a minority of people with HCV infection that incur healthcare costs. This is consistent with the population based data on natural history of HCV infection that serious liver disease only occurs in a small number of people after many years of infection. On the other hand, once liver disease is established, hepatitis C can require intensive healthcare resources and generate very high costs, particularly in patients with end stage liver disease.

Patients with advanced stage liver disease that present with portal hypertension and hepatic decompensation, as manifested by ascites, hepatic encephalopathy, or gastrointestinal bleeding, necessitates inpatient care, including liver transplantation. Thus, data on patients referred for and undergoing liver transplantation (OLT) for end-stage liver disease or hepatocellular carcinoma reflect the most severe degree of morbidity associated with HCV.

Using mathematical models, Armstrong et al estimated that the prevalence of HCV in the US peaked in the mid-1990's at slightly above 2.0% and would slowly decline to 1.0% by 2030. Furthermore, the model predicted that the proportion of people with infection for 20 years or longer would increase with an anticipated peak in the mid-2010's. Indeed, there is a projected four-fold increase in the number of persons with longstanding (more than two decades) infection between 1990 and 2015. The significance of this projection is that persons with long duration of infection are at risk to develop serious complications of chronic liver disease such as cirrhosis and HCC (liver cancer).

Based on population prevalence estimates (NHANES) are available data on the rate of disease progression, Wong et al projected healthcare costs related to hepatitis C will continue to rise steadily for the next 10 years.

Given the substantial burden of HCV infection, antiviral therapy may make economic sense as well as provide clinical benefits of halting or reversing disease progression and improving quality of life. Several studies have addressed the economic justification of antiviral therapy (Dusheiki, Bennett, Kim, Younossi, Wong, Buti, Sennafait, Sagmeister) From these studies, several conclusions may be drawn. Interferon based antiviral therapy is in general within the accepted range of cost-effectiveness ratio.

However, there are several factors that can potentially effect the cost-effectiveness of HCV therapy substantially. These include factors that effect the likelihood of future development of end stage liver disease, such as age and rate of progression and those that effect the likelihood of viral response including genotype and fibrosis stage. As there are still uncertainties about the rate of disease progress and treatment response in individual patients in real practice setting (as opposed to randomized trials), clinical judgement in the selection of treatment candidate is still an important element that determines the cost-effectiveness of antiviral therapy for hepatitis C.

## Diagnostic Tests

Various tests are available for the diagnosis and monitoring of hepatitis C infection. Tests that detect antibody against the virus include EIA's and the recombinant assays (RIBAs). The same HCV antigens are used in both EIAs and RIBAs. Targeted amplification techniques using either polymerase chain reaction (PCR) or transcription-mediated amplification (TMA) have been developed to detect HCV RNA. Liver biopsy can provide direct histological assessment of liver injury due to HCV but cannot be used to diagnose HCV infection.

### HCV Serologic Assays

EIA tests are reproducible, inexpensive, and FDA-approved for use in the diagnosis of HCV. They are suitable for screening at-risk populations and are recommended as the initial test for patients with clinical liver disease. The very high sensitivity and specificity of third-generation EIAs (sensitivity greater than 99 percent, specificity 99 percent) obviate the need for a confirmatory RIBA in the diagnosis of individual patients, particularly those with risk factors for HCV. RIBA remains a useful supplemental assay in the setting of large-scale HCV screening of blood products.

#### **Estimated costs (2002) of diagnostic tests are:**

Antibody testing with testing and pre- and post-test counseling:	\$22
Home Access with unlimited test/counsel:	\$72
Confirmatory HCV RNA viral load testing:	\$75-\$125
Standard CBC with CHEM panel & LFTs:	\$10 (varies)
Genotyping; cheaper in bulk, covered by studies	\$275-\$400
Liver Biopsy: In Radiologist office: \$1200; in hospital:	\$1500
Biopsy with CT guidance:	\$1500-\$1800
Vaccination for Hep A:	\$72
Vaccination for Hep B (over 3 series)	\$400
Vaccination for TwinRx: Hep A & B (also 2 series; price varies):	\$250

## Qualitative HCV Assays

Persistent HCV infection in a patient with a positive EIA test should be confirmed by a qualitative HCV RNA assay. A single positive qualitative assay for HCV RNA confirms active HCV replication, but a single negative assay does not prove that the patient is not viremic. A follow-up qualitative HCV RNA should be performed to confirm the absence of active HCV replication. Once HCV infection is confirmed, repeat testing for qualitative HCV RNA by qualitative PCR is not helpful in the management of untreated patients. Almost all patients remain viremic, and a negative result may merely reflect a transient decline in viral titer below the level of detection of the assay.

## Quantitative HCV Assays

Testing for HCV RNA level (or viral load) by a quantitative assay, either quantitative PCR (qPCR) or branched DNA signal amplification assay (bDNA), can provide accurate information on HCV viral titer. An HCV RNA standard has been introduced to permit normalization of reported viral titers in international units (IU). The reported IU does not represent the actual number of viral particles between assays. Significant variability exists between assays. The clinical utility of serial HCV viral titers in a patient is predicted on continued use of the same specific quantitative assay used in the initial determination of the viral titer. While there is little correlation between disease severity or disease progression with the absolute titer of HCV RNA, quantitative determination of the HCV titer provides important information in assessing response to treatment.



Testing for serum ALT levels is the most inexpensive and non-invasive means of assessing disease activity. However, a single determination of ALT gives limited information about the severity of the underlying liver disease. In most studies, a weak association exists between the degree of ALT elevation and severity of the histopathological findings on liver biopsy. Serial determination of ALT levels over time may provide a better means of assessing liver injury, but the accuracy of this approach has not been shown. Serial determinations of ALT levels can be recommended as a general means of monitoring patients but is not adequate to assess progression to cirrhosis.

Various noninvasive tests have been examined for monitoring patients with chronic hepatitis C infection. These include routinely available laboratory tests, such as liver-associated chemistries, platelet count, prothrombin time, as well as specific serum markers of fibrosis and inflammation that are not currently widely available or well validated. No single tests or panel of serologic markers can provide an accurate assessment of intermediate stages of hepatic fibrosis. Similarly, quantitative tests of liver function and radiologic imaging of the liver are sensitive for diagnosing advanced cirrhosis but are not useful in assessing hepatic fibrosis and early cirrhosis.

## Liver Biopsy

Liver biopsy yields information on fibrosis and histological assessment that is not obtainable by any other means. Various noninvasive methods based on biochemical or serologic tests have been evaluated in several studies. Liver enzymes have shown little value in predicting fibrosis. Extracellular matrix tests do predict severe stages of fibrosis but cannot consistently classify intermediate stages of fibrosis. Moreover, only liver biopsy provides information on possible contributions of iron, steatosis, and concurrent alcoholic liver disease to the progression of chronic hepatitis C toward cirrhosis.

The information obtained on liver biopsy does allow the affected individuals to make a more informed choice with regard to initiation or postponement of antiviral treatment. Adult or pediatric

patients with persistently normal or slightly elevated ALT and minimal or no fibrosis on liver biopsy may be reassured of a favorable prognosis and decide to defer antiviral treatment.

Since a favorable response to current antiviral therapy in patients infected with genotypes 2 and 3 occurs in 80 percent, the necessity of routine pretreatment liver biopsy in these patients is debatable or provider-dependent. Baseline assessment of liver histology offers the standard by which subsequent comparisons may be made. Expert opinion on the appropriate interval for subsequent evaluations varies from 3-5 years.



## Hepatocellular Cancer Screening

HCC complicates cirrhosis secondary to HCV. It is estimated that HCC occurs after the development of cirrhosis at a rate varying from 0.5 to 5 percent t per year, with a 1% per year average in the United States. Few studies examine specific screening strategies for HCC in patients with advanced HCV. Alpha fetoprotein (AFP) and ultrasound every 6 months were used in a single study of patients with cirrhosis secondary to HCV.

## Genotyping

This information is useful for making treatment decisions, such as which medications to use and how long treatment should last. The most commonly used classifications of hepatitis C consist of eleven main genotypes and are composed of many subtypes. It is believed that that within an HCV sub-type, several million quasispecies may exist.

These main types are: 1,2,3,4,5,6,7,8,9,10 and 11.

Most common subtypes are: 1a,1b,1c; 2a,2b,2c; 3a,3b; 4a,4b,4c,4d,4e; 5a

Genotype 1, the most prevalent in the United States (70%) is the most resistant to current treatments. Genotype 2 & 3 (30% prevalence in US) have significantly higher response rates and usually require shorter treatment lengths.

## Current Treatments for Hepatitis C

[Excerpted National Institutes of Health Consensus Development Conference Statement 2002]

The highest response rates have been achieved with PEG-interferon in combination with ribavirin. Genotype determinations now influence treatment decisions. Methods of genotyping include PCR-based techniques and, more recently, less expensive serotyping (antibody) assays. Sustained viral response (SVR), defined by the absence of detectable qualitative HCV RNA in the serum by RT-PCR 24 weeks after the end of treatment, is currently the best indicator of effective therapy.

Three large pivotal trials have examined the efficacy of PEG-interferon in treatment of chronic HCV infection. These trials excluded patients with decompensated cirrhosis and other comorbid conditions. Factors associated with successful therapy include genotypes other than 1, lower baseline viral load, and less fibrosis or inflammation on liver biopsy. In all three trials, an SVR of 42-46 percent was achieved for genotype 1 using a higher dose of PEG-interferon and ribavirin for 48 weeks. An SVR of 76 to 82 percent was achieved for patients with genotypes 2 and 3. It appears that 24 weeks of treatment and a lower dose of ribavirin is adequate for genotypes 2 and 3. Early viral response (EVR), defined as a minimum 2-log decrease in viral load during the first 12-24 weeks of treatment has been identified as predictive in SVR. Those that fail to achieve an EVR have only a small chance of achieving a SVR even if therapy is continued for a full year.

Although SVR has not yet been correlated with improved survival because of necessary follow-up, the absence of detectable serum HCV RNA has been correlated with resolution of liver injury, reduction in hepatic fibrosis, and a very low likelihood of recurrent HCV infection. Additionally, in two large recent studies from Japan, interferon treatment was associated with a reduction in the development of hepatocellular carcinoma, a finding that was more pronounced among patients with SVR.

**Average Treatment Costs (12 months):**

Peg-interferon	\$1400	mth
Ribavirin	\$ 1000	mth
Compounded Ribavirin	\$250-350	mth

## Re-treatment of Patients

Patients who may benefit from re-treatment include those whose HCV infection failed to achieve SVR. Decisions regarding re-treatment should be based upon: (1) previous type of response (2) the previous therapy and the difference in potency of the new therapy, (3) the severity of the underlying liver disease, (4) viral genotype and other predictive factors for response, and (5) tolerance of previous therapy and adherence.

Patients whose HCV infection does not respond to current optimal therapy with PEG-interferon and ribavirin present a significant problem, particularly in the presence of advanced fibrosis or cirrhosis. The possible role of maintenance therapy with PEG-interferon alone in preventing further progression of cirrhosis, clinical decompensation, or development of hepatocellular carcinoma is currently the focus of a large, multicenter United States trial, HALT-C which is sponsored by the National Institute of Health (NIH).

## Side Effects of Treatment

In the registration trials of PEG-interferon and ribavirin, significant side effects were noted that resulted in discontinuation of treatment in approximately 20 percent of subjects. Major side effects include influenza-like symptoms, hematological abnormalities, and neuropsychiatric symptoms. The education of patients and caregivers about side effects and their prospective management is an integral part of treatment. Frequent monitoring of HCV therapy is necessary. Antidepressants, such as selective serotonin reuptake inhibitors, may be useful in the management of less severe depression associated with antiviral therapy. Treatment of cytopenias with hematopoietic growth factors may be useful and may prevent dose reduction or drug discontinuation. Severe hemolysis may occur in patients with renal insufficiency.

## Which Patients Should be Treated?

[Excerpted National Institutes of Health Consensus Development Conference Statement 2002]

All patients with chronic hepatitis C are potential candidates for antiviral therapy. Treatment is recommended for patients who are at increased risk for progression to cirrhosis. These patients are characterized by measurable HCV RNA, a liver biopsy with portal or bridging fibrosis, and at least moderate inflammation and necrosis; the majority has persisted elevated ALT values. In some patient populations, the risks and benefits of therapy are less clear and should be determined on an individual basis.

Many patients with chronic HCV have been ineligible for trials because of injection drug use (IDU), alcohol abuse, age, and a number of comorbid medical and neuropsychiatric conditions.

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Efforts should be made to increase availability of the best current treatment to these patients. Because a large number of HCV-infected persons in the United States are incarcerated, strategies should be developed to prevent, diagnose, and treat these individuals.

## Normal ALT

Approximately 30 percent of patients with chronic HCV have normal ALT levels, and another 40 percent have ALT levels less than two times the upper limits of normal. Although most of these patients have disease that is histologically mild, some patients may progress to advanced fibrosis and cirrhosis. Experts differ on whether to biopsy and treat these patients.

Numerous factors must be considered in recommending treatment, including favorable genotype, presence of hepatic fibrosis, patient motivation, symptoms, severity of comorbid illness, and patient's age. SVR (Sustained Viral response) rates do not differ in patients with normal or mildly elevated ALT when treated with interferon monotherapy. Studies of Peg-interferon with ribavirin have not been completed in patients with normal ALT levels.

## Mild Liver Disease

In patients with persistent ALT elevations, but with no fibrosis and minimal necroinflammatory changes, progression to cirrhosis is likely to be slow; these patients should be monitored periodically.

## Advanced Liver Disease

SVR is lower in patients with advanced liver disease than in patients without cirrhosis. An important goal of treatment with advanced liver disease is to delay histological disease progression, which is being evaluated in the NIH-sponsored HALT-C trial. Patients with decompensated cirrhosis should be referred to clinical trials until safety and efficacy data of treatment are established, or they should be considered for liver transplantation.

## Injection Drug Users

Recent experience has demonstrated the feasibility and effectiveness of treating HCV in people who use illicit injection drugs (known as injection drug users or IDUs). This is important because IDUs comprise the largest group of hepatitis C patients in the United States, and successful treatment may reduce transmission. Management of HCV-infected IDUs is enhanced by linking IDUs to drug treatment programs. Efforts should be made to promote collaboration between experts in HCV, the County Alcohol and Drug Program, and local substance-abuse providers. HCV therapy has been successful even when patients have not been abstinent from continued drug use or are on daily methadone.

## HIV Coinfection

All HIV infected persons should be screened for HCV. Patients with chronic hepatitis C and concurrent HIV infection may have accelerated course of HCV disease. Therefore, although there are no HCV therapies specifically approved for patients coinfecting with HIV, these patients should be considered for treatment. Thus far, studies have enrolled only patients with stable HIV infection and well-compensated liver disease. In coinfecting persons, an SVR can be achieved with HCV treatment.



## Alcohol and HCV

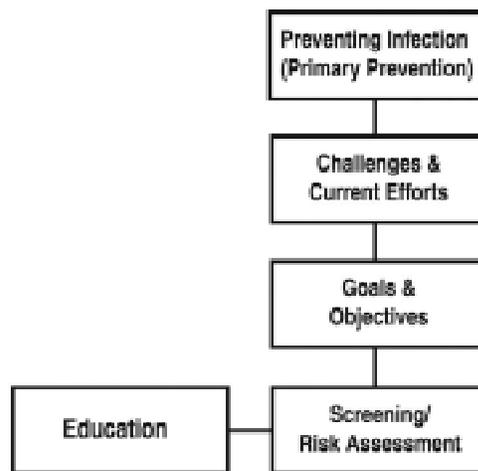
Alcohol is an important cofactor in disease progression of HCV liver disease to cirrhosis and HCC. A history of alcohol abuse is not an absolute contraindication to therapy; however, continued alcohol use during therapy adversely affects the response to treatment. Treatment of HCV should be performed in conjunction with efforts to treat alcohol abuse or dependence.

## Extra-hepatic Manifestations of Hepatitis C

Problems with HCV can occur outside the liver. Thyroiditis and diabetes may be related to infection of the thyroid and pancreas, respectively. Porphyria cutanea tarda (PCT) is an abnormality in the hepatic production of porphyrins (light sensitive pigments) that cause a severe rash in sun exposed areas. However, most of the extrahepatic manifestations of HCV are due to immune complexes formed from viral proteins and antibodies in blood. Cryoglobulinemia is one type of immune complex causing reddish rash (prominent on lower legs) and membranous glomerulonephritis (potentially causing renal failure). Other problems from other types of immune complexes include arthritis and other types of rashes. Lichen planus is another problem manifested by skin disease and mouth ulcers.



## Preventing Infection (Primary Prevention)



### Goal:

Significantly decrease the number of people newly infected with hepatitis C by using primary prevention strategies.

### Overview:

Primary prevention involves those strategies used to reduce the risk of contracting hepatitis C. This includes counseling the hepatitis C infected persons on methods to prevent the transmission of their infection to other people. Primary prevention is the process of providing information and education services to healthy populations to allow them to make decisions that will reduce their risk and protect themselves from contracting the virus.

**Prevention steps that may help accomplish reduction in new infection are:**

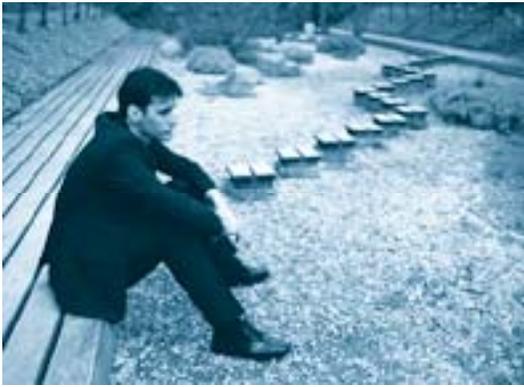
- *Risk assessments and testing of blood, plasma, organ, tissue and semen donations;*
- *Risk assessments, testing, counseling and education to those who have engaged in high-risk activities such as sharing needles for drug use, vitamins, or other substances;*
- *Risk assessment, testing, counseling and education of individuals who have had percutaneous (through the skin) exposures to blood in health care or emergency situations;*
- *Risk-reduction education, counseling and services; and*
- *Implementation and maintenance of infection control practices.*

**An important goal of primary prevention/preventing infection is to encourage high-risk individuals to participate in risk assessments, testing and counseling. This can be accomplished through prevention interventions that include:**

- *Public education using strategies such as targeted media campaigns; efforts aimed at high-risk populations, hepatitis C-infected persons, and members of their family and social networks.*

**To be effective, a prevention strategy for hepatitis C must reach:**

- *Individuals who have injected drugs, including those who injected once or more times many years ago and do not consider themselves to be drug users; injecting drug users who share needles*
- *Persons who are or have been on long-term hemodialysis;*
- *Recipients of blood transfusions or organ transplants prior to July 1992, or anyone that received clotting factor or agents known to contain blood products produced prior to 1987;*
- *Children born to hepatitis-C positive mothers;*
- *General public, including those who may be infected with hepatitis C;*
- *War-era veterans*
- *Persons of populations from countries of high prevalence of hepatitis C that have received medical treatment outside the United States*
- *Mandatory reporting*
- *Access to funding.*



## Challenges to Prevention

At the present time, Santa Barbara County lacks adequate epidemiological data about the magnitude of the hepatitis C problems in its region. It is very difficult to raise awareness and obtain support for disease prevention without thorough information. Although some public support has come forward concerning public awareness and intervention, in general there is a lack of overall public interest for programs serving substance users, the mentally ill, and persons infected with hepatitis C, largely due to stigma associated with the major risk group. It has been difficult to reach the different

language and cultural groups within the county due to both the lack of data about the needs and the challenges to address all of the various groups in need of different presentations of the same information.

## Current Prevention Efforts:

### Current limited prevention efforts throughout the county have included:

- *Risk assessment and testing of blood, plasma, organ, tissue and semen donations;*
- *Risk assessment, testing and education of individuals who have engaged in high-risk activities such as injecting drug use;*
- *Risk assessment, testing and education of individuals who have had percutaneous (through the skin) exposures to blood in health care or emergency situations;*
- *Risk-reduction counseling and services;*
- *Awareness of the importance of maintaining infection control practices;*
- *Targeted annual education programs for the general public and providers;*
- *Needle exchange/harm reduction;*
- *Community patient support groups and education programs.*

## Objective #1

Santa Barbara County requires medical providers to report both acute and chronic hepatitis C to the county health department.

- Standardize the procedures for reporting hepatitis C cases, including making information easier to report and requirements easier to understand;
- Secure a staff position within the health department responsible for monitoring surveillance from medical providers;
- Provide ongoing education about reportable diseases to all medical providers;
- Review notification process for persons identified to be anti-body positive, through notifying healthcare providers and blood banks.

## Objective #2

Research is an important component of surveillance. Through the collection of information about hepatitis C, important information such as the role of transmission, effective prevention, and personal and economic burdens will improve.

- Develop a surveillance data collection system to be used by various organizations serving the public in Santa Barbara County. The data can be used to understand the nature of hepatitis C in the community and to monitor the effectiveness of programs and strategies.
- Develop a computer based data collection program, which will include a complete directory of hepatitis C data and research in Santa Barbara County.
- Collaborate with other county programs in our region, surrounding states and federal agencies, such as the CDC and the National Institutes of Health to participate in a larger pool of information serving the national agenda about hepatitis C.

## Screening:

Limited risk assessment and testing has been done in Santa Barbara County. This has been accomplished primarily through current county service providers and private physicians.

## Objective #1

Develop community accessible screening and testing sites.

- Partner with existing organizations that serve groups at high-risk for hepatitis C to commence risk assessment processes and testing.

## Objective #2

Develop a standard risk assessment questionnaire to be used by all agencies and organizations providing assessment and/or testing of people.

- Identify existing risk assessment questionnaires already being used by other organizations to enhance for use and adapt for Santa Barbara County.

## Objective #3

Counseling is a very integral part of disease education. It is important that counseling strategies and policies be developed and used prior to testing and as a follow-up for testing results.

- Develop a counseling program that includes pre-and post-test counseling guidelines.
- Develop a county-wide system of documenting and tracking risk assessment responses and testing.
- Support hepatitis C awareness and educational activities through community-based organizations.



# Managing Disease (Secondary Prevention)

## Goal:

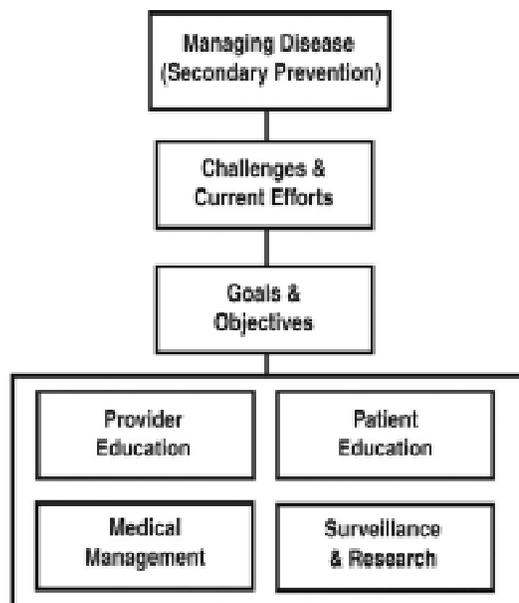
Identify hepatitis C-infected persons in Santa Barbara County and offer or refer persons to quality healthcare in the region that is accessible and affordable to prevent or minimize the consequences of hepatitis C infection.

## Overview:

Secondary prevention encompasses strategies to test individuals at risk for hepatitis C infection and to provide them with proper healthcare access and case management.

For the persons chronically infected with hepatitis C, provide education and resources that will encourage patients to advocate for wellness and prevent the spread of the disease.

In accordance with the Centers for Disease Control and Prevention, hepatitis C testing should be offered to people most likely infected with the virus and that testing should be accompanied by appropriate counseling and medical follow-up.



## Routine testing should be available to:

- *Persons who ever injected drugs, even once or a few times many years ago and who do not consider themselves drug users;*
- *Drug users who share needles, or other paraphernalia;*
- *Persons who received clotting factor produced before 1987 or who have ever received long-term hemodialysis;*
- *Recipients of transfusions or organ transplants before July 1992;*
- *Health care or emergency workers after possible exposure to hepatitis C-positive blood;*
- *Persons incarcerated in correctional facilities; and*
- *Children born to hepatitis C-positive women.*

Persons who test positive for hepatitis C antibody should see a medical provider to have a confirmatory test performed. The most common test used today is the HCV RNA by PCR. This blood test will confirm the actual presence of the hepatitis C virus. It is also important that standardized pre- and-post test counseling guidelines be developed and followed.

Due to the significance of hepatitis A and hepatitis B viruses on an infected hepatitis C liver, it is recommended that persons with chronic liver disease be vaccinated against hepatitis A and hepatitis B if the person is not known to have been previously exposed to these other liver viruses.

Treatment efficacy has greatly improved in the past few years. With the arrival of pegylated interferons and ribavirin, and available data from clinical trials on the potential benefit of these therapies, it is important that medical providers and persons chronically infected understand the treatment options, consequences, and potential benefits of therapy.

It is important in disease management to include a counseling and referral system to those patients who may be struggling with drug and/or alcohol abuse.

People infected with hepatitis C often experience a variety of social and psychosocial challenges, including depression. Strategies need to be developed and made accessible for those patients to have the support they need to minimize the challenges. Training of individuals providing these services is essential. Community-based support organizations need to be identified and provided as a source of help for patients.

#### **Challenges to Managing Disease (Secondary Prevention):**

- *Limited specialty physicians to manage HCV patients*
- *Comprehensive education of Primary Care Physicians to evaluate and co-manage patients with HCV in partnerships with specialists*
- *Train and educate providers with interest in co-managing HCV*
- *Lack of coordination for the provision of resources*
- *Support groups and educational information to provide for non-English speaking persons*
- *Identify patient services and resources that include substance abuse, support and recovery programs, co-infection, and psycho-social with disease management*
- *Access and funding to increase Hepatitis A & B vaccinations to patients with hepatitis C*
- *Maintaining patients on treatment and in providing support for patients challenged with side effects on HCV therapies*
- *Funding for diagnostic and treatment care services for the uninsured and under-insured.*

#### **Current Managing Disease (Secondary Prevention) Efforts:**

*The following are provided on a limited basis:*

- *Vaccinations of Hepatitis A & B provided to patients with chronic liver disease*
- *Some screening and testing of HIV infected individuals at infectious disease clinics*
- *County-wide education for providers*
- *Risk assessment and referral for high risk individuals in harm-reduction setting*
- *Support groups/educational programs for patients, family members, and friends*
- *Program entitled "Hepatitis C 101" for newly diagnosed patients and partners*
- *Infection control education for nurses, social workers, and counselors*
- *Blood Banks - donors are screened and donated blood is tested by community blood center for indicators of HCV and other blood-borne pathogens.*

**In order to develop an effective secondary prevention plan, it has been determined that key component areas must be addressed and objectives developed within each of the component areas:**

- *Education*
- *Surveillance and Research*
- *Screening*
- *Medical Management.*

## Provider Education:

### Objective #1

Appoint an education committee whose members will assess the various objectives in accordance with the strategic plan. The Committee will propose new concepts and will identify existing resources that may be utilized to meet the goals of the community.

- Identify materials that are culturally and linguistically appropriate.

### Objective #2

Develop HCV case review forum for physicians in small group settings.

- Identify and recruit HCV specialist as forum leader CME credits
- Regional meetings (north and south county)
- Hold regular scheduled forums
- Create and nurture physician network
- Identify funding support for forums.

### Objective #3

Provide disease management information (where to find resources) to community on a regular basis

- Post DDW and AASLD meeting journal clubs
- Newsletter
- Forums
- Website/links
- Medical society newsletters (Health Authority/Sansum)
- Grand rounds.

## Patient Education:

### Objective #1

Appoint an education committee whose members will assess the various objectives in accordance with the strategic plan. The Committee will propose new concepts and will identify existing resources that may be utilized to meet the goals of the community.

- Identify materials that are culturally and linguistically appropriate.

### Objective #2

Identify resources for patients that cover topics of self-help and empowerment. Include information on access to medication, diet, and management of symptoms, insurance program funds for under-insured, physician referrals and clinical trials, and recovery programs. Create a resource directory that would be disseminated through participating stakeholders, and other providers.

### Objective #3

Encourage and promote patient support group activities and include these resources in all materials about hepatitis C made available to the public. Include information as part of health care education training programs.

### Objective #4

Provide the patient education on both Western and alternative therapies

### Objective #5

Provide some element of focus on education of legislators and activities that will allow and encourage those infected and affected by hepatitis C to participate.

### Objective #6

There is documented evidence concerning discrimination, or the perception of discrimination against people with hepatitis C. These experiences may be work related, or related to health care insurance, and experiences with family members, friends, or neighbors.

- Identify legal services that will help patients respond to possible discrimination because they are hepatitis C positive
- Prepare and distribute workplace related educational materials that specifically address the magnitude of the problem and risk factors of transmission.

## Screening:

### Objective #1

Identify existing resources, or develop new resources that would educate physicians and risk service providers about the need to identify individuals that should be tested for hepatitis C.

- Utilize simple messages and slogan statements about risk factors and appropriate testing for the virus, pre-test and post-test counseling guidelines and medical follow-up.
- Identify partners (other organizations) that have messages consistent with the goals of the Santa Barbara Task Force.

### Objective #2

Identify financial resources within the county, seek new funding resources, and identify potential partners to assist in the screening effort in Santa Barbara County.

### Objective #3

Promote education and training within the public health sector including nurses, counselors, outreach workers, and medical support staff.

### Objective #4

Identify areas within the county where education and medical management are at highest risk, meaning education and medical services that are not being obtained by the citizens.

- Assess the scope of the outreach problem
- Consider development of special education programs and materials.

## Surveillance and Research:

### Goal:

To measure the burden of disease and its complications, compile accurate, comprehensive and useful data on hepatitis C that will direct and support primary and secondary prevention, education and training, and long-term medical management and rehabilitation.

#### Challenges to Surveillance and Research:

- *Inconsistent physician reporting*
- *No staff to report/enforce or support physician compliance*
- *Passive surveillance system.*

### Objective #1

Create a system of epidemiological studies working with local experts concerning populations affected in Santa Barbara County. Collaborate and promote epidemiological research in SB county.

### Objective #2

Coordinate current and future testing efforts to be implemented and improve survey systems in order to monitor impact of screening and measure prevalence of risk factors of disease and, develop consistent risk assessments that would be utilized by all organizations conducting blood test screenings for hepatitis C to assist the county in further identification of the magnitude of the problem.

### Objective #3

Enhance compliance with current passive reporting systems.

### Objective #4

Develop web-based directory of research on SB county residents (collect pockets of data).

## Medical Management:

### Goal:

The goal of medical management is to engage the patient, family members and providers in a disease management plan to improve the long-term outcome and quality of life (Q.O.L.) for the individual. At the present time, most hepatitis C patients are seen in primary care settings by PCP, internal medicine specialties, specialty clinics by gastroenterologists or liver specialists, some of which are outside of Santa Barbara County.

Hepatitis C puts a significant strain on the patient and his/her family members due to the traumatic impact of the diagnosis and the lack of consistent messages about medical management and treatment options. It has become increasingly more important to have appropriate educational tools to meet the needs of the individuals who are supporting those infected, their family members and for the prevention of new infections.

#### Challenges to Medical Management:

- *Lack of access to healthcare providers*
- *Lack of adequately trained providers*
- *Cost of care*
- *Patient compliance*
- *Risk stratifications*
- *Limited drug treatment facilities*
- *Number of GI Specialists in county vs number of potentially infected*
- *No clinical trials.*

### **Current Medical Management:**

- *Professional and patient education*
- *Support groups*
- *Passive surveillance*
- *Screenings.*

### **Objective #1**

Identify existing education training programs, benefits counseling, and patient treatment compliance models that can be used for providers and patients.

### **Objective #2**

Identify a speaker's bureau of qualified experts trained in hepatitis C medical management, whose membership will devote specialized time to areas of educational and clinical need; i.e. (Also see Professional Education Goals) training other providers, assisting in outreach service clinics.

- Define standard of care for hepatitis patients (see Overview of Hepatitis C and NIH Consensus Statement 2002: [www.consensus.nih.gov](http://www.consensus.nih.gov) )
- Encourage vaccinations of hepatitis A & B for HCV+ patients.

### **Objective #3**

Continue to host with partners, ongoing hepatitis C conferences for medical providers and allied health personnel, with emphasis in teaching medical management and patient advocacy.

- Train providers within the county to manage hepatitis C infected patients.

### **Objective #4**

Identify and/ or establish key resource person(s) at community based organizations, agencies and Public Health Department that can assist patients with access to healthcare, treatment, support and educational services.

- Establish benefits counselor positions
- Identify and integrate patient advocates into programs
- Promote/establish treatment "sponsors" programs for patients
- Encourage/promote patient referrals to support groups/educational programs.

### **Objective #5**

Promote integration of HCV services into existing providers (HIV, STD, correctional and jail facilities, veterans services, methadone and other substance abuse programs)

- Establish HCV programs for substance abuse treatment facilities
- Establish additional substance abuse services for HCV +patients
- Encourage collaboration between service providers.

### **Objective #6**

Establish clinical trials for treatment of hepatitis C in Santa Barbara County.

- Promote collaboration with established liver disease medical facilities and educational institutions (i.e. UCLA, Cedar Sinai, USC, CPMC, UCSF, Stanford, etc.) with local medical providers.

### **Objective #7**

Establish web-based information and resource identification system for existing and potential providers of hepatitis C services, as well as for patient resource and referral.

### **Objective #8**

Most of the public health sector staff are involved in health education activities at many levels. It is important that opportunities be provided to assess educational goals and practices within each healthcare setting. Plan staff meetings or other structured activities for assessment of hepatitis C experiences.

## GLOSSARY OF TERMS:

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**Acquired Immunodeficiency Syndrome (AIDS):** disease caused by the human immunodeficiency syndrome virus (HIV). AIDS weakens the body's defenses making people vulnerable to attack from a range of other diseases.

**Acute Hepatitis:** Initial stage of liver inflammation, which occurs suddenly. Persons with HCV are less likely to have acute hepatitis, which often has no symptoms, than persons with hepatitis caused by other viruses.

**Addiction:** A primary, chronic, neurobiological disease, the development and manifestations of which are influenced by genetic, psychosocial, and environmental factors. Addiction is characterized by continuous or periodic impaired control over use of the substance, preoccupation with its use, and continued use despite adverse consequences and distortions in thinking.

**Albumin:** A blood protein manufactured by the liver. It is an indicator of the liver's ability to produce proteins in general and is essential in maintaining healthy circulation. Albumin acts like sponge to hold fluid, salt and water within the blood vessels and may actually help maintain the structural integrity of the vessels themselves. If there is not sufficient albumin – as happens when the liver develops cirrhosis – fluid leaks out of the vessels, causing swelling in the ankles and feet (edema).

**Alpha-fetoprotein (AFP):** A blood test for cancer tumors in patients with liver disease.

**Alkaline phosphatase:** An enzyme that is responsible for phosphorus metabolism and delivering energy to the body's cells. High levels in the blood may indicate blockage in the common bile duct or within the smaller bile ducts inside the liver. Alkaline phosphatase is also found in bones, the placenta, and the intestines and therefore another enzyme (GGT) is measured at the same time to confirm results.

**ALT (alanine aminotransferase) levels:** An enzyme found in the liver cells. When the liver is damaged, ALT escapes out into the blood. Therefore, ALT levels in the blood indicate possible liver damage. ALT levels are often measured in routine blood testing, this test used to be called the SGPT. Very high levels suggest hepatitis or another liver disease that has killed many liver cells. Moderately high levels may be a sign of conditions as chronic hepatitis, gallbladder disease or mononucleosis. Slightly elevated levels may indicate cirrhosis or a heart attack. Many medications (such as aspirin, barbiturates, narcotics, alcohol, and some immunosuppressant drugs) can cause ALT levels to rise. Previously, physicians relied on ALT levels exclusively to guide decisions on when and how to treat chronic hepatitis and liver damage. However, since it is known that persons with HCV can suffer liver damage and still have normal ALT levels, doctors should use other indicators in addition to ALT to monitor progress.

**Ammonia:** A blood toxin. High blood levels indicate the liver is unable to clean dangerous toxins from the body.

**Anemia:** A condition caused by chronic low red blood levels, indicated by pallor and weakness.

**Antibody (AB):** A substance created during the immune system response that helps disable foreign substances. Antibody "sticks" to antigen, the marked foreign substance. Antibody helps disable the foreign substance and signals to certain white blood cells to ingest the substance to help complete the immune response. The presence of antibodies indicates the body was exposed to a disease, but may not have it now.

**Antigen:** A foreign invader in the body that is marked so that white blood cells and other substances can find and disable it.

**Anti-HCV:** The antibody for the hepatitis C virus.

**Antiviral drugs:** Medications that work by killing the virus responsible for a given disease. Antivirals are relatively new. Several have recently been developed for treating HIV/AIDS. The knowledge gained from creating these drugs is now being put to use in research for antivirals that will combat HCV. Antiviral drugs currently approved for treating HCV are alpha interferon and ribavirin. Other antivirals are currently in clinical trials (human testing) to determine whether they are effective in treating HCV.

**Arthralgias:** The aches and pains associated with inflammation in the joints, possibly caused by immune response to the presence of the HCV virus.

**Ascites:** Fluid accumulation and swelling of the abdomen caused by blocked blood flow through the liver. This condition is associated with chronic hepatitis and other liver problems such as cirrhosis. Treatment includes reducing salt intake and taking diuretics.

**Aspartate aminotransferase (AST):** An enzyme often measured in routine blood testing. This test used to be called the SGOT. Like ALT, AST can escape out into the blood when the liver is damaged. But it can also leak out inside muscle tissue, including the heart. This means that a high AST level in and of itself does not necessarily indicate a liver problem.

**Barriers:** Conditions that affect the HCV community's ability to carry out recommended actions and reach objectives.

**Bilirubin:** A waste product that comes from a breakdown of heme, the central oxygen-carrying molecule in red blood cells. If not converted into a water-soluble substance by the liver, this yellowish liquid can act as a toxin, producing jaundice-the most vivid symptom of hepatitis.

**Case Management:** A system in which a professional works with a client or patient to assure that they get diagnosis, treatment, support services, monitoring and referral, as needed.

**Chronic hepatitis:** Liver inflammation that lasts more than 6 months and does not go away. Many people have chronic hepatitis and don't realize it because it may not present symptoms for decades. Over time chronic hepatitis can lead to severe liver damage.

**Cirrhosis:** A liver condition in which normal liver cells die and are replaced by scar tissue. This new tissue is unable to perform the various functions carried out by normal liver cells. Scar tissue also blocks blood from flowing through the liver. As scar tissue builds, the liver gradually performs fewer and fewer of its vital functions. Fluid can accumulate in the abdomen (ascites) and back up into veins near the esophagus. These veins can burst, causing the person with cirrhosis to vomit up blood. Because the liver cannot remove toxic substances, they build up in the skin (leading to jaundice and itching).

**Clinical trials:** Tests on humans conducted to determine whether a drug is both safe and effective in treating a particular condition. Clinical trials are usually one of the last stages in drug development before FDA approval.

**Clotting Factors:** Chemicals manufactured by the liver that enables blood to clot when needed, such as when skin is damaged by a cut. Clotting factors are absent in people with hemophilia, requiring use of clotting factor from donated blood. Before HCV was isolated, using clotting factor placed hemophiliacs at risk for acquiring HCV. Since 1991, blood has been screened for HCV.

**Cognitive dysfunction:** A condition that can occur as a result of having long term liver problems. As toxins build up throughout the body and the brain, thinking is less clear. A person may become confused and disoriented, often called brain fog by patients with HCV.

**Combination Therapy:** Treatment for hepatitis that includes the combination of interferon and ribavirin.

**Cryoglobulinemia:** Inflammation caused by antibody-type proteins in the blood (serum) directed against HCV. They can gel or clump at low temperatures and cause a number of harmful side effects to the skin, kidney, eye, brain and heart. A purplish or blue indicator on the skin where bleeding (ruptured blood vessels) has occurred is called purpura. Damage to the extremities-nose, ears, hands and feet- from poor blood flow causes red feet and "red hands", or Raynaud's disease. A clustering or blocking of blood vessels in the kidneys causes glomerulonephritis. This can lead to kidney failure, dialysis and transplantation.

**Discordant:** not having the same serostatus, for example a couple in which one partner is HCV positive and the other is HCV negative.

**Edema:** Swelling of the hands and feet due to fluid retention, a symptom of chronic hepatitis.

**Encephalopathy:** A state of mental confusion or drowsiness caused by toxic elements in the blood, left untreated coma results. Treatment includes medication, reducing or eliminating animal protein (which release ammonia), and controlling intestinal bleeding.

**Enzyme:** A substance that helps cells generate energy without being used up itself. Many enzymes are found in the liver, each with a different function. When the live enzyme alanine aminotransferase (ALT) or aspartate aminotransferase (AST) are found in the blood, liver damage is suspected.

**Epidemiological profile:** The gathering of data in order to establish when and where diseases are occurring, who is affected, and what behaviors or exposures place individuals at risk; provides evidence from which to develop and target prevention activities and programs.

**Fibromyalgia:** Pain in the muscles and fibrous connective tissue; a common complaint of patients with HCV.

**Fibrosis:** One of the effects of HCV on the liver. Fibrosis occurs as old tissue is destroyed and replaced by new, nonfunctional scar tissue. Over time, the liver begins to function less and blood becomes backed up in the main vein and surrounding channels in the liver.

**Food and Drug Administration (FDA):** An agency within the Department of Health and Human Services of the U.S. government. The FDA is responsible for regulating and approving all drugs (prescription and over-the-counter) in the U.S.

**Fulminant Hepatitis:** End stage hepatitis or liver failure.

**Gastric Esophageal Variceal Bleeding:** A life threatening condition sometimes brought on by portal hypertension (restricted blood flow through the liver) where blood vessels in the esophagus or stomach rupture. The bleeding is difficult to stop, and surgery to repair the rupture can also be life threatening.

interest and expertise in treating liver problems, since the liver is considered part of the body's digestive system. Gastroenterologists may perform certain diagnostic procedures, but are not trained to do surgery.

**Genotypes:** The various forms that a virus may take. HCV comes in many genotypes, making it harder to diagnose and treat than other types of hepatitis. Known genotypes of HCV and their predominate locations are type 1, type 2 and type 3 (worldwide); type 4 (Middle East and Africa); type 5 (South Africa); and type 6 (Asia).

**Gamma-glutamyl transpeptidase (GGT):** An enzyme used to metabolize the amino acid glutamate which effects tissue oxidation and that in high levels in the blood may indicate blockage in the common bile duct or within the smaller bile ducts inside the liver itself. High levels may also indicate liver cancer. Alcohol use can dramatically affect results. GGT is usually measured along with another similar enzyme, alanine phosphatase.

**Goal:** More broadly stated than an objective, goals are impact- and outcome- oriented. The goal summarizes the overall plan to address problems as well as the anticipated results of the strategic actions.

**Harm Reduction:** A set of practical strategies, including clean needle and syringe exchange, that reduce negative consequences of drug use, incorporating a spectrum of approaches from safer use, to managed use, to abstinence.

**HCV:** Hepatitis C virus, the virus that causes the disease called hepatitis C. HCV is classified as a RNA virus.

**HEDIS (Health Plan and Employer Data Information Set)** A system that requires reporting of certain health conditions so that services and prevalence may be monitored for compliance with regulations.

**Hemophilia:** A condition that occurs when the body is unable to manufacture a factor that helps the blood clot. Many people with hemophilia have HCV, due to using clotting factors created from infected donated blood.

**Hepatitis:** Inflammation of the liver. Can be caused by viruses, drugs, or alcohol.

**Hepatitis A:** Formally called infectious hepatitis because its virus spreads through fecal contaminated water and food. It is more common in developing countries, but is also found in the U.S. There is a recent vaccine to prevent hepatitis A. Gamma globulin can also be taken to help protect against exposure for a shorter period of time. HAV is almost never chronic and rarely leads to permanent liver damage.

**Hepatitis B:** Formally called serum hepatitis because its virus, HBV, spreads through blood and other body fluids. It is often considered the most serious form of hepatitis. Hepatitis B can be transmitted through sexual contact, transfusion, or injection drug use and from a pregnant woman to her baby. Most people recover from hepatitis B, but some may retain chronic infection. A vaccine to prevent hepatitis B has been available since 1982. A special gamma globulin can also be taken to protect against exposure. High-risk groups are IV drug users, people having transfusions before 1991, and men having sex with men.

**Hepatitis C:** Formally called non-A, non-B (NANB) hepatitis. Risk group includes those with blood transfusions prior to 1991, hemophiliacs, IV drug users, health care workers (needle stick) and emergency health care personnel. HCV spreads through the blood and is the most common form of hepatitis. The initial illness is often so slight that most people don't even notice it, yet few people recover completely. Most people with HCV go on to develop chronic hepatitis infection. Currently, there is no vaccine to prevent HCV. Gamma globulin does not seem to protect against HCV.

**Hepatitis D:** Formally called delta hepatitis. It is only found along with hepatitis B and is rare in the U.S.

**Hepatitis E:** Formally called enteric or epidemic non-A, non-B hepatitis. It is similar to hepatitis A. It is rare in the U.S. and is most common in areas around the Indian Ocean.

**Hepatitis G:** This strain has only recently been discovered. The HGV virus (there are at least three subtypes of this virus) spreads through blood and is often found along with HBV, HCV, and HIV (the virus that leads to AIDS). In otherwise healthy people, HGV seems to cause no problems. It is thought that HGV may simply be a sort of marker for other, yet-undiscovered hepatitis viruses.

**Hepatocellular carcinoma (HCC):** A type of cancer of the liver that is associated with HCV.

**Hepatologist:** A medical doctor (MD) or doctor of osteopathy (DO) who has received additional training in the diagnosis and treatment of liver problems, including surgery. There are not many practicing hepatologists. Most are located in large university research centers or large urban medical centers.

**Human immunodeficiency virus (HIV):** A family of viruses that causes AIDS (acquired immunodeficiency syndrome), in which the body's defenses are weakened, leaving you open to attack from various diseases.

**Immune system:** The body defense system that protects against foreign invaders (e.g., bacteria, viruses) Some immune defenses are non-specific (e.g., phagocytosis), while others are directed against specific invaders (e.g., antibody production). Organs of the immune system are lymph nodes, spleen, thymus, and tonsils.

**Incidence:** The number of new cases of infection that occur in a given population over a period of time.

**Infectious hepatitis:** Another name for hepatitis A.

**Inflammation:** One of the results of the immune response to a foreign invader. As fluid, cells, and other substances accumulate at the site of the invasion, swelling occurs.

**Interferon:** Alpha interferon, beta interferon, and gamma interferon are used to combat several types of cancer and diseases thought to be caused by viruses, such as multiple sclerosis, rheumatoid arthritis, and hepatitis C. An antiviral protein that is a naturally occurring immune system response; it “interferes” with the viral replication of infected cells, hence, its name.

**Jaundice:** A yellowing of the eyes and skin that occurs as bilirubin builds up in the tissues. Normally, bilirubin is broken down and removed by the liver.

**Lactulose:** A medication used to help rid the blood of excess ammonia. Ammonia is a byproduct of the digestion and use of protein (commonly found in red meat). When a person has cirrhosis, the liver may be less able to process proteins properly, leading to a rise in the ammonia level in the blood.

**Lichten Planus:** A dermatological disorder generally attributed to liver dysfunction. It is characterized by groups of small and irregular bumps with flat-topped surfaces that usually appear on the wrists, shins, face, lower back and genital areas.

**Liver:** An organ in the abdomen that is responsible for processing all food that passes out of the digestive tract, storing and distributing nutrients, and breaking down toxic substances in the body.

**Liver biopsy:** The process whereby a piece of the liver is surgically removed for clinical study. It is considered the gold standard in diagnosing HCV.

**Liver function tests (LFTs):** Blood tests that measure a range of substances normally found in the liver, including ALT, AST, alkaline phosphatase, GGT, bilirubin, serum albumin, prothrombin time, and other substances related to more rare liver conditions.

**Mission:** The fundamental reason or purpose for the existence of an organization.

**Neomycin:** A medication used to help rid the blood of excess ammonia. Ammonia is a byproduct of the digestion and use of protein. When a person has cirrhosis, the liver may be less able to process proteins properly, leading to a rise in the ammonia level in the blood.

**Neuropathy:** A nerve disease that triggers pain or numbness, usually in the feet or hands and is brought on by long term infection with HCV.

**Non-A non-B (NANB) hepatitis:** Another name for hepatitis C.

**Nonspecific:** The term used by doctors to describe symptoms that are general in nature and could be associated with a number of different medical conditions. Examples of nonspecific symptoms include flu-like symptoms, fatigue, and sleep problems. Many nonspecific symptoms are associated with HCV.

**Nucleoside analogue:** A type of antiviral medication that blocks the virus’s ability to replicate and may alter the immune system cells that fight viruses, making them more effective. Ribavirin is a nucleoside analogue.

**Objective:** A specific statement of a measurable amount of progress toward goal attainment; objectives are specific, measurable, attainable, realistic, and time bound. An objective states in measurable terms what will be accomplished to help meet a goal and provides the target to evaluate program results.

**Pegylated Interferon:** A long-acting time release form of interferon.

**Polymerase Chain Reaction Assay Test (PCR):** A method used to detect the RNA virus directly. The test measures viral load, that is, how many viruses exist in one milliliter of blood.

**Porphyria Cutanea Tarda (PCT):** A dermatological disorder generally attributed to “iron overload” found in several forms of chronic liver disease including HCV. A condition in which porphyrins build up in the body leading to symptoms includes photosensitivity, skin damage, and discoloration.

**Portal hypertension:** A condition that occurs in 65% of people with cirrhosis. As blood is less able to flow through the liver, it backs up into the vein that connects the intestines and liver (portal vein). As blood continues to back up into surrounding veins, smaller vessels can burst, leading to life threatening bleeding indicated by vomiting blood.

**Prevalence:** The number of infected individuals in a population at a given point in time.

**Primary prevention:** The process of providing information and education services to healthy populations to allow them to make decisions that will reduce their risk and protect them from contracting illness or disease.

**Prospective study:** a clinical trial in which participants are selected and their progression is followed over time. Contrast with retrospective study.

**Prothrombin time (Protime or PT):** A test to determine how long it takes for your blood to clot. The liver makes clotting factors, the proteins for your blood to clotting. If the liver is damaged, it takes longer for your blood to clot.

**Pruritis:** Itching of the skin that occurs when the liver cannot remove toxins from the blood and, consequently, the skin. Since antihistamines and lotions have no effect on pruritis caused by hepatitis, incapacitating pruritis can be reason enough for a liver transplant.

**Purpura:** A disease caused by blood leaking from blood vessels. It is characterized by purple or reddish brown spots on the skin and mucous membranes.

**Rebetron:** The brand name of a combination of ribavirin and alpha interferon.

**Recombinant Immunoblot Assay Test (RIBA):** A method of detecting antibodies against HCV antigens using an immunoblot format. It is less likely to give a false positive than ELISA.

**Recovery:** The process of regaining a healthy balance in the lives of those directly or indirectly affected by substance use or Hepatitis C.

**Referred pain:** Pressure on nerves in the liver and abdomen caused by swelling can also cause sensations of pain around the right shoulder. This may occur most frequently after liver biopsy.

**Remission:** A state in which the virus and symptoms seem to disappear. Interferon therapy and possibly some alternative therapies cause remission for some people with HCV, however, if therapy is discontinued the virus may reappear.

**Retrospective study:** a study based on medical records, looking backward in time at events that happened in the past. Contrast with prospective study.

**Reverse Transcription PCR (RT-PCR):** Generally accepted as the most sensitive test for detecting HCV.

**Rheumatoid arthritis (RA):** A condition caused when the body's immune system attacks the lining (synovia) of the joints. Symptoms include joint pain, swelling, and loss of function of joints. Like HCV, people with RA often feel extreme fatigue, depression, and other symptoms associated with immune system disorders.

**Secondary prevention:** Strategies used to identify, counsel, and test individuals most likely to be infected and provide them with appropriate medical and case management.

**Sexually transmitted disease (STD):** Any of a number of diseases that are spread through sexual intercourse. STD's include HIV/AIDS, genital herpes, vaginitis, chlamydia, gonorrhea, syphilis, condyloma, and many other diseases. It is thought that HCV may in some cases be transmitted though sexual intercourse; however, incidence of acquiring HCV is extremely low in persons involved in a mutually monogamous relationship with a partner who has HCV.

**Solutions:** Ways to address, diminish, or eliminate barriers.

**Stakeholders:** Potential partners from various groups, including public and private organizations, constituencies, funding organizations and others that in some way influence or affected by prevention and management efforts.

**Strategic Actions/Recommendations:** The specific activities that will be carried out to meet goals and objectives.

**Substance Abuse:** Alcohol and other drug abuse

**Target populations:** Groups within the community, region, or state impacted by the issues identified in the problem statement; groups whose needs and situations are addressed through the objectives and recommendations.

**Thyroiditis:** Inflammation of the thyroid that can result in hyper- or hypothyroid-ism.

**Transfusion:** Giving blood from a donor to a patient whom has experienced blood loss. Transfusion was one of the major ways of transmitting HCV until a test was devised in 1991 to test donated blood for the virus.

**Viral hepatitis:** Hepatitis caused by a virus (such as hepatitis A and hepatitis C). Hepatitis can also be caused by some medications.

**Virus:** An extremely small organism, invisible to the eye and even to all but the strongest microscopes. There are two classes of viruses: DNA (deoxyribonucleic acid) and RNA (ribonucleic acid).

**Vision:** The collective sense of where the community wants to go in three years in prevention, management, support, and why.

# Santa Barbara County Hepatitis C Resources

Currently, a comprehensive Santa Barbara County HCV Resource Guide is being developed by "Back to Life" and will be completed by summer 2003. If you would like to list your organization or business as a resource in this guide, please contact "Back to Life" at our web site or number below.

## **"Back to Life" Hepatitis C "Education, Prevention & Support Project**

Monthly MFCC/RN/LSW facilitated support groups in Santa Barbara, Santa Maria, Lompoc and Ojai. "Hep C 101" RN facilitated educational programs, speaker programs, provider programs. Resource and referral. Patient and provider information: [www.hepatitisupport.org](http://www.hepatitisupport.org), provider information: [www.sbhcvtaskforce.org](http://www.sbhcvtaskforce.org), 5662 Calle Real, PMB 368, Goleta, CA 93117 (805) 692-2860

## **Santa Barbara Neighborhood Clinics**

Call for testing sites, free HCV antibody testing and counseling. Low cost /sliding scale medical care and referral to specialists. Isla Vista Medical Clinic, Westside and Carrillo Clinics. 970 Embarcadero del Mar, Isla Vista, CA 93117 (805) 968-1511 X110

## **AIDS Project Central Coast (Program of Pacific Pride)**

Syringe exchange, harm reduction and education to intravenous substance users at risk for HCV/HIV infection. Substance use and addiction treatment resources and referrals for those living with and at-risk for HIV/HCV. Wed. 5:30-7pm 126 E. Haley, Suite A-11, Santa Barbara, CA 93101, 963-3636 Wed. 4-7pm, North County: 819 West Church St., Santa Maria (805) 349-9947

## **Santa Barbara County Health Care Services - Santa Barbara**

345 Camino del Remedio, Santa Barbara, CA 93110 (805) 681-5365

## **Santa Barbara County Health Care Services - Santa Maria**

2115 S. Centerpointe Parkway, Santa Maria, CA 93455 (805) 346-7230

## **Santa Barbara County Health Care Services – Lompoc**

301 North R St. Lompoc, CA 93436 (805) 737-6400

## **USEFUL WEBSITES/ INFO:**

[medlineplus.nlm.nih.gov/medlineplus/hepatitisc.html](http://medlineplus.nlm.nih.gov/medlineplus/hepatitisc.html) - links and information

[www.hepccalifornia.org](http://www.hepccalifornia.org) - links and info

[www.hepatitisresources-calif.org](http://www.hepatitisresources-calif.org) - links and info

[www.californiahcvtaskforce.org](http://www.californiahcvtaskforce.org) - California HCV Task Force

[www.hepcchallenge.org/manual](http://www.hepcchallenge.org/manual) - compilation of HCV treatment choice

[www.hepcesn.org/comboguide.htm](http://www.hepcesn.org/comboguide.htm) - Patient guide for combination treatment

[www.hcvadvocate.org](http://www.hcvadvocate.org) - educational materials, educational programs and mthly newsletter

[www.hepcassoc.org](http://www.hepcassoc.org) - links and info

[www.hivandhepatitis.com](http://www.hivandhepatitis.com)

[www.natap.org](http://www.natap.org) - excellent info on co-infection and updates on HCV

[www.oasisclinic.org](http://www.oasisclinic.org) - HCV treatment for substance abuse patients

[www.hcvprisonnews.org](http://www.hcvprisonnews.org)

## **NATIONAL ORGANIZATIONS / INFORMATION**

2002 HCV Consensus Statement - [www.consensus.nih.gov/cons/116/116cdc\\_intro.htm](http://www.consensus.nih.gov/cons/116/116cdc_intro.htm)

California HCV Strategic Plan - [www.dhs.ca.gov/ps/dcdc/html/publicat.htm](http://www.dhs.ca.gov/ps/dcdc/html/publicat.htm)

CDC Hepatitis Hotline 1-800-443-7232 - [www.cdc.gov/ncidod/diseases/hepatitis/c/index.htm](http://www.cdc.gov/ncidod/diseases/hepatitis/c/index.htm)

Hep C Connection Hotline 1-800-522-4372 - [www.hepc-connection.org](http://www.hepc-connection.org)

Hepatitis Foundation International 1-800-891-0707 - [www.hepfi.org](http://www.hepfi.org)

American Liver Foundation 1-800-GO-LIVER - [www.liverfoundation.org](http://www.liverfoundation.org)

Latino Organization for Liver Awareness - [www.lola-national.org/](http://www.lola-national.org/)

United Network for Organ Sharing UNOS - [www.unos.org](http://www.unos.org)

Strategic Plan sponsored by:

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