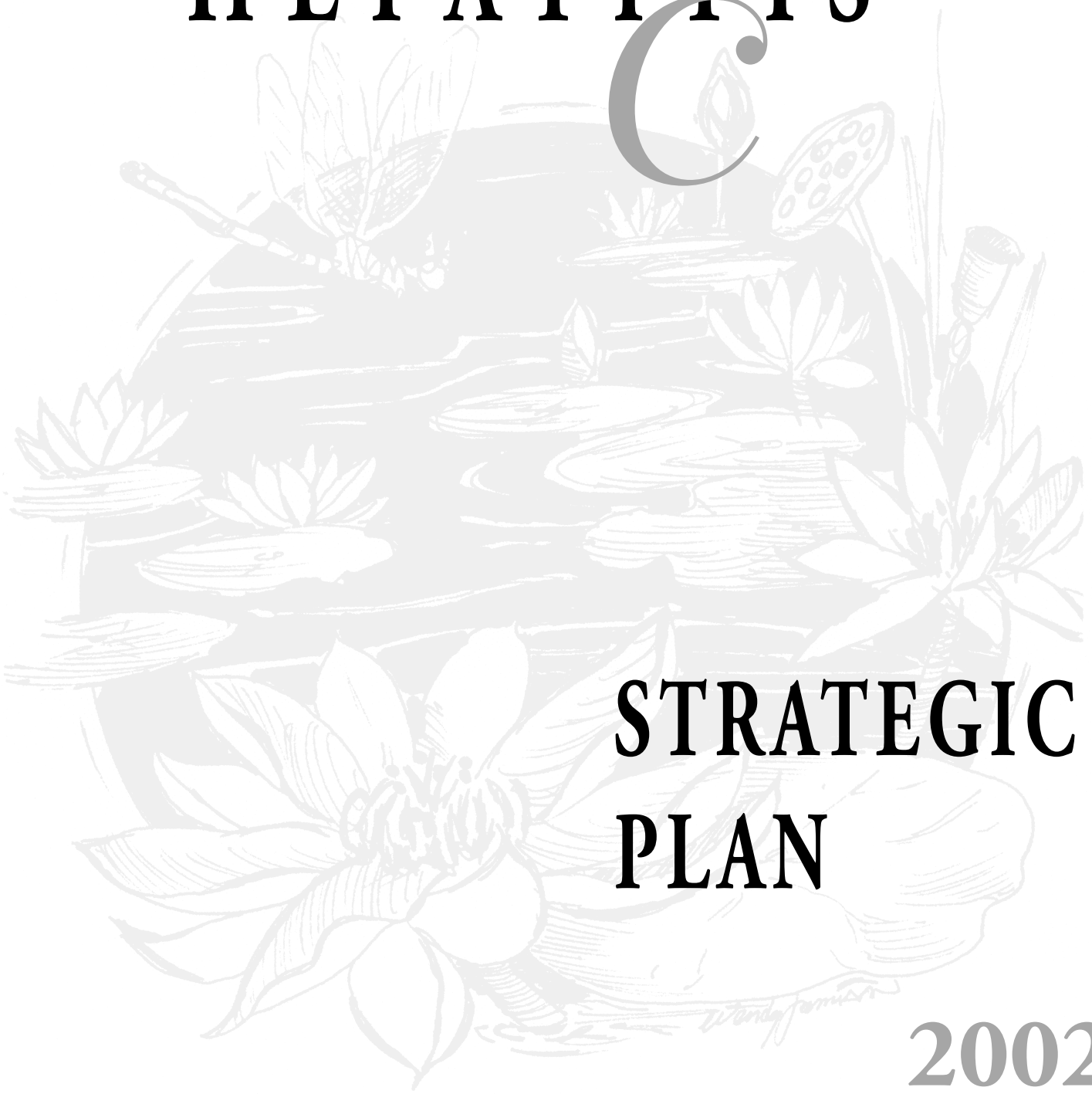
HEPATITIS C

STRATEGIC PLAN



2002

Orange County, California

About the floral images:
Wendy Jamison, the artist, is a native of Santa Barbara, California.
The Artwork is a memorial to her cousin who passed away from Hepatitis C.

ACKNOWLEDGEMENTS

The Advisory Council on Hepatitis C for Orange County became a reality due to the dedicated effort of key people and organizations. Our gratitude is extended to Back to Life and Carol Craig for starting the work and facilitating the meetings, in addition to editing and producing the final product. Special appreciation to each and every member who gave countless hours to develop the ideas and recommendations that make up the Strategic Plan.

We give special acknowledgment to the members of the Steering Committee: Dr. John Hoefs, University of California, Irvine who provided the educational overview of hepatitis C, which included treatment approaches and the complexity of the disease; and Dr. Hildy Meyers, Communicable Disease Control and Epidemiology, Orange County Health Care Agency for providing the committee with an insight on hepatitis C and its impact from a public health perspective. The plan also benefited significantly from the expertise provided to the Council by the Orange County Health Care Agency, Dr. Penny Weismuller, Amy Dale, and Susan Sullivan, R.N. These individuals brought various talents and expertise to the table, including health education, infection control, and infectious disease concepts. We appreciate key component articles written by Dr. Hoefs and Dr. Meyers included as part of the plan. Pearl Jemison-Smith, long time recognized patient advocate for HIV, brought HIV/HCV coinfection reality to the table and was instrumental in the development of the advocacy component that became part of the final plan. A special thank you to Dan Gleason, AIDS Services Foundation for bringing HIV history to the committee, including similarities in all patients living with potentially life-threatening diseases. Significant contribution was made by REACH program members Mitch Cherness and James Roser, who brought passion for the project and expertise to each meeting in the area of substance abuse, HIV and hepatitis C, populations who are underserved, and obstacles to screening and education. We extend our warm thank you to Gwen Mason and the Mariposa Women's Center for coordinating meeting facilities.

We must also express gratitude for the Department of Health Services, State of California, for the work they accomplished in the year 2000 with the development of a State Strategic Plan.

The Steering Committee and the Advisory Council members brought energy and vision to the long and rewarding process. Collectively, these people have helped to make Orange County a leader in improving what we know, what we need to know and accomplish, and how we can effect change.

Strategic Plan Facilitator
Carol Craig

Editing and Production
California Hepatitis C Resource Center/Back to Life Orange County

Design
Kenny the Printer, Irvine, California

Printing of this publication was made possible by the generosity of:
Roche
California Hepatitis C Resource Center/Back to Life Orange County
Orange County Health Care Agency

TABLE OF CONTENTS

ADVISORY COUNCIL ON HEPATITIS C
ORANGE COUNTY

Carol Craig*
Director
California Hepatitis C Resource Center/Back to Life
A Tides Center Project

Mark Horton, M.D., M.S.P.H.
Director of Public Health
Orange County Health Care Agency

Hildy Meyers, M.D.*
Epidemiology and Assessment
Orange County Health Care Agency

John Hoefs, M.D.*
Associate Professor of Medicine
UCI Medical Center

Penny Weismuller, R.N., Dr.P.H.*
Division Manager, Disease Control & Epidemeology
Orange County Health Care Agency

Marti Witford
Director of Clinical Services
Huntington Beach Community Clinic

Mitch Cherness*
Service Chief
R.E.A.C.H
Orange County Health Care Agency

David K. Imagawa, M.M. Ph.D., F.A.C.S.
Chief, Transplantation
UCI Medical Center

Gary Sladek
Hepatitis C Support Group Coordinator
Saddleback Church

James Roser*
Health Education Associate
R.E.A.C.H.
Orange County Health Care Agency

Susan Sullivan, R.N., M.S.N.
Orange County Health Care Agency
Disease Control & Epidemeology

Mary Hale
Program Manager
Alcohol & Drug Abuse Services
Orange County Health Care Agency

Pearl Jemison-Smith*
Advocate

Amy Dale*
Division Manager
Health Promotion
Orange County Health Care Agency

Howard Friend
Director of Adult Services
Phoenix House

Phillip Falcetti, M.P.H.
Director, Community Alliance Network
National Council on Alcoholism and Drug Dependence

Chip Pope
Program Supervisor II
R.E.A.C.H.
Orange County Health Care Agency

Sandra Guerra
Community Health Educator
Huntington Beach Community Clinic

Gwen Mason*
Clinical Coordinator
Mariposa Women's Center

George M. Chitty
Orange County Red Cross

Thuan Tran
HCA/HIV Programs

Dan Gleason*
Executive Director
AIDS Service Foundation

Darolyn Underwood, R.N., B.S.N.
Senior Public Health Nurse, ACT Team
Orange County Health Care Agency

** Steering Committee Members*

HOW TO USE THIS STRATEGIC PLAN

The Hepatitis C Strategic Plan for Orange County was written to be used by all groups and organizations that provide care or service for those infected and affected by hepatitis C. The strategic plan process brought many groups and individuals to the table to discuss hepatitis C and the ways in which we might improve conditions for everyone.

The Plan is to be used as a guideline to help groups, organizations and individuals plan activities and to encourage and empower people to undertake efforts to improve the lives of those infected with hepatitis C in Orange County. The ultimate goals are prevent new infections, identify those who may have the disease and provide them with access to testing, and to medically manage the chronically infected.

It is also important to the Advisory Council that this plan helps everyone develop an understanding of hepatitis C and its impact in Orange County and beyond.

The members developed Mission and Vision Statements, and Guiding Principles, and identified the following key component areas:

- Primary Prevention
- Secondary Prevention
- Public Education
- Provider Education
- Advocacy
- Surveillance
- Medical Management and Rehabilitation

Within each of the component areas, definitions are provided, current efforts were outlined, and objectives for each component were identified. These objectives are in order of priority as determined by the Advisory Council on Hepatitis C.

For definitions of terms that are used throughout the plan, including limited medical terms that may be helpful to you, please refer to the Glossary at the back of this plan.

On behalf of the Steering Committee and the entire Advisory Council on Hepatitis C, we hope you find this document useful.

We encourage you to make any comments or suggestions for our future meetings and updates by sending an email to BacktoLife@emailaccount.com. The plan will be monitored over the next 3 years. Please contact us if you or your organization have or will be starting some of the work outlined in this plan. Together, we will make a difference.

For additional copies of the plan, please visit *California Hepatitis C Resource Center* web site at www.hepcCalifornia.org (proceed to *California Information*).

MISSION STATEMENT, VISION STATEMENT AND GUIDING PRINCIPLES

MISSION STATEMENT:

The purpose of the Hepatitis C Strategic Plan is to outline a detailed approach for Orange County which is consistent with the plan for the State of California that will provide for a coordinated, comprehensive, culturally appropriate, and systematic approach to prevent the spread of hepatitis C infections in Orange County, limit the progression and health complications of hepatitis C related liver disease, and advocate for hepatitis C policies and resources.

VISION STATEMENT:

The vision is a local effort which will be supported by various agencies and groups in partnership to provide services for those individuals that are infected and affected by hepatitis C and all other persons in need of services. By the year 2005, Orange County will have developed and implemented an effective strategic plan that will embrace and define education, research, access, treatment, screening, advocacy, prevention, surveillance/data, needs assessments, targeted populations, screening, and resources to assure:

- A working understanding of the scope of hepatitis C in Orange County and mechanisms for ongoing evaluation and assessment is in operation
- Patients, providers, policy makers, media and the general public will be appropriately knowledgeable about hepatitis C
- Resources have been developed and identified to accomplish the vision
- Continuum of preventive and care services is accessible to the public
- Hepatitis C related research is integrated into the strategic plan components
- Active advocacy is ongoing for policies that result in prevention and control of hepatitis C

GUIDING PRINCIPLES:

The State of California developed and adopted guiding principles during the state process in the year 2000 when a state plan was developed that could be used as a resource for local agencies.

According to these principles, the strategic plan:

Represents a comprehensive approach to hepatitis C that recognizes the inherent value of all individuals regardless of infection

- Builds hepatitis C services on the existing infrastructure for HIV/STD, methadone, alcohol and other drug treatment systems for common target groups, and where appropriate, provides hepatitis C specific services to those individuals outside of, and not served by the existing infrastructure
- Recognizes that there are groups that are disproportionately affected by hepatitis C and makes funding allocations to decrease disparities
- Advocates for hepatitis C services that are culturally and linguistically appropriate, accessible and non-discriminatory
- Recognizes the social and economic impact of hepatitis C infections on families, communities, and on our health care system
- Recognizes that hepatitis C prevention is a shared responsibility between the public and private sector
- Supports actions steps and policies that are evidence-based
- Ensures confidentiality
- Improvement in quality of life for those with hepatitis C infection

OVERVIEW OF HEPATITIS C

John Carl Hoefs, M.D.
Associate Professor of Medicine - Director of the Liver Disease Program
University of California Irvine

Hepatitis C is a relatively new diagnosis, but not a new disease. Chronic hepatitis is an inflammatory condition of the liver detected indirectly by abnormal enzymes in blood primarily AST (SGOT) and/or ALT (SGPT) or directly by liver biopsy. By contrast with acute hepatitis, evidence of inflammation in chronic hepatitis is present for more than 6 months. Many causes of chronic hepatitis have been systematically discovered over the last 50 years since liver enzymes were first reported to indicate hepatic inflammation. The first disease described was "Lupoid" hepatitis (now known as autoimmune chronic active hepatitis). However, all the discovered causes of hepatitis in the 1970 accounted for a small percentage until evidence for chronic viral disease was reported. Viral hepatitis was discovered as transmissible orally or by blood products and labeled "infectious" and "serum" hepatitis, respectively. Infectious hepatitis was eventually found to be due to hepatitis A and does not cause chronic liver disease. "Serum hepatitis" could cause acute hepatitis, but was also able to produce chronic hepatitis. The first cause of serum hepatitis was found to be due to hepatitis B. However, this agent accounted for only a small percent of all cases of chronic viral hepatitis. Thus, the term non-A, non-B chronic hepatitis referred to presumed "serum" hepatitis not due to hepatitis B. Many patients today were originally labeled non-A, non-B (NANB) chronic hepatitis.

It became clear in the 1980's that the majority of cases of chronic hepatitis were due to this non-A, non-B agent and a search for the presumed viral cause was started. Therapeutic trials with interferon were actually started in the mid-1980's prior to the identification of the agent. In the early 1990's, the viral RNA structure was determined and the hepatitis C antibody test produced. The agent that reacted with this test was called hepatitis C and the antibody was found in most patients with NANB chronic hepatitis. Nearly 90 % of the cases of NANB chronic hepatitis were due to this agent.

What is hepatitis C?

The genetic material of a virus can be either deoxyribonucleic acid (DNA) such as found in the nucleus of a cell or ribonucleic acid (RNA) similar to messenger molecules from DNA found in the cytoplasm of the cell. Hepatitis C is a small RNA virus of the Flaviovirus type. Many other infective agents that cause chronic disease are RNA viruses including the hepatitis D (Delta) virus (co-infects with hepatitis B), hepatitis E virus (does not cause chronic infection) and HIV virus. RNA viruses that have been thought to be other NANB agents such as hepatitis F virus or G virus have been found to be variants of hepatitis C or non-hepatitis agents. The hepatitis B virus is the only hepatitis virus of the DNA type. There is still a search for other hepatitis viruses (non-A, non-B, non-C).

The hepatitis C virus enters the body by direct inoculation and rarely across intact oral, vaginal or rectal exposure. Once in the body, the virus circulates to the liver where it enters the liver cell. It reproduces in the cytoplasm using the cell's own RNA and DNA machinery. The virus replicates its RNA (creating new strands of hepatitis C RNA) and produces proteins that are specific for HCV. The new viral RNA is encapsulated within the new viral proteins within the endoplasmic reticulum and excreted through the golgi apparatus as intact infective virus. The excreted virus infects other hepatic cells until the activated anti-viral systems balance the production of the virus by the destruction of cells containing the virus.

The hepatitis C may cause direct injury to the liver cell, but more likely serves as a focus for an immunologic attack by the body. The immunologic attack is mediated by lymphocytes (T cells) producing cell-mediated damage with an attempt by the body to kill all viral containing cells. If the body is successful, the patient experiences acute hepatitis (which may be assymptomatic) with no residual clinical consequences except presence of hepatitis C antibody. If the immunologic attack is insufficient to kill all the cells containing the virus, there is an ongoing attack that we call chronic hepatitis. The final result is the inflammatory reaction noted on liver biopsy with characteristic lymphoid follicles/aggregates and inter-phase hepatitis (piece-meal necrosis). A chronic infection develops in 75-85% of patients whose livers are exposed to the hepatitis C virus.

Hepatitis C may infect other cells besides hepatocytes (lymphocytes, thyroid, etc) although clinical problems rarely develop from such infection. Furthermore, antigen/antibody complexes may form, causing injury at distant sites such as the kidneys (membranous glomerulonephritis), rashes (cryoglobulinemia) and thrombocytopenia (immune related). These extra-hepatic manifestations occur in less than 2% of patients.

Who is most at risk for hepatitis C?

Direct inoculation is the primary method of entry into the body. Thus, intravenous drug abuse (IVDA) and transfusions would be efficient in transmitting hepatitis C. Even sharing straws (trauma to the nasal mucosa with sub-clinical bleeding) and other equipment during cocaine use or tattooing may cause transmission. This may include sterile needles used in tattooing if the dye solutions used for tattooing contain virus. Exposure through vaginal or rectal intercourse is common in HIV and HBV, but is much less common with HCV. However, intimate contact that may cause sub-clinical direct inoculation (trauma during intercourse, etc) may be possible although other methods of exchanging body secretions such as sharing tooth-brushes or shaving equipment seem more likely to account for the increased exposure of spouses.

Approximately, 70% of IVDA or hemophiliacs transfused before 1980 have been exposed to HCV. Transfusion with HCV-containing blood products results in infection > 70% of the time. Up to 10% of blood products contained HCV in the early 1980s and transfusions were a significant source of HCV at that time. Blood transfusion prior to 1980 is a strong risk factor for HCV. However, less than 1 in 60,000 units of blood are infected at the present time due to excellent screening methods.

Although intimate contact such as found with a sexual relationship is associated with HCV transmission, the exact role of intercourse is unclear. Other behaviors associated with intimate contact may be more important than intercourse such as sharing shaving equipment or toothbrushes. These behaviors are more common in a low socioeconomic stratum of patients. Thirty to 40 % of patients do not have evidence of a specific behavior associated with transmission of the virus except for low socio-economic status.

Tests for hepatitis C

HCV antibody

Testing for hepatitis C has undergone rapid evolution since the discovery of the hepatitis C antibody and its clinical availability in the early 1990s. This first test was relatively restricted, measuring an antibody in blood to a single protein derived from the c-100 portion of the HCV genome. Improvements were made with the detection of antibodies to proteins derived from multiple regions of the viral genome. The test became more specific and more sensitive. However, there were both false positive reactions (positive when the virus was not present) and false negative reactions (negative when the virus was present). The first problem was overcome with the RIBA test which tested each of the proteins separately to determine whether it was a true positive or not. However, some patients who had been exposed to the virus and were cured remained antibody-positive. This true positive test was not associated with active infection. Despite improvements in the HCV antibody test, there were always some false positive test, true positives without active infection and false negative tests. A better test was needed.

The current HCV antibody test can be assessed in the presence or absence of abnormal liver tests (ALT). A positive hepatitis C antibody is associated with active infection in > 98% of patients with ALT, but only 50% of patients with a positive hepatitis C antibody will have active infection if the liver tests are normal. Furthermore, immune suppressed patients (due to HIV or chronic renal failure) with active infection and ALT will be positive in only 80% (a high false negative rate). The main advantage of the hepatitis C antibody is the relatively low cost allowing screening of blood and ease of testing in the routine laboratory.

HCV RNA by PCR

The HCV antibody detects the presence of an antibody reaction to the virus and is, therefore, an indirect test of the presence of the virus. A direct test of the presence of the virus is preferable. The next test developed was the hepatitis C RNA by polymerase chain reaction (PCR). The RNA in a sample is converted to a C-DNA fragment and this molecule is replicated artificially through a large number of cycles (approximately 38) to expand the number of RNA strands present. The detection of a carefully prepared sample was highly specific for the presence of the virus and a negative test was correlated with the absence of the virus. However, the test was so sensitive that contamination was a problem. A laboratory interested in hepatitis C might have small amounts of hepatitis C RNA in the dust of the laboratory that could contaminate a sample, causing negative samples to be positive. This problem has been overcome and the present qualitative PCR for hepatitis C RNA detects reliably < 100 molecules (copies) of the virus in 1-milliliter (ml) of blood. All cases of active hepatitis C have values greater than this. Thus, all cases of active hepatitis C are positive by this test.

A negative test of the qualitative PCR indicates the virus is not present in blood and, therefore, unlikely to be present in the body. It rules out the presence of an active infection in an untreated patient. The goal of treatment is to produce a negative HCV RNA by qualitative PCR and this result is labeled a sustained response if the PCR becomes negative during treatment and remains negative 6 months after treatment is stopped.

Quantitative Hepatitis C RNA Levels

There are many difficulties in measuring the exact amount of HCV RNA in serum or blood. Quantitative PCR (Q-PCR) amplifies the C-DNA product with the assumption that the initial amount of RNA is the major determinant of the final amplification detected. One problem is that of contamination, but that has been overcome with time. Another is the efficiency of converting from RNA in a sample to C-DNA, which is then amplified and measured in the PCR system. The efficiency refers to the percent of RNA that is converted to C-DNA. In some people, it may be 10% and others 70%. Furthermore, the efficiency differed between genotypes. It is difficult to state with certainty the initial amounts without knowing the efficiency in an individual patient. Thus, quantitative PCR was initially laborious and subject to contamination. Only meticulous and expensive laboratories were able to measure the levels reliably. However, the general efficiency is known now and some techniques assess the efficiency in the individual patient. Therefore, quantitative PCR has become reliable enough for detection in the routine laboratory. This has also reduced the cost.

Prior to the availability of a cost-effective quantitative PCR method, another technique was developed to measure small quantities of viral RNA in blood. This was called signal amplification

(SA). The major innovation of this technique was the attachment of a molecule to the small amount of RNA present and then the signal was amplified by attaching more and more molecules that gave off a signal that could be measured. The amount of signal was generally related to the amount of molecules in the original sample. That is why it was called signal amplification in contrast to the product amplification by PCR.

The lower limit of reliable RNA detection by SA is 200,000 copies/ml compared with 2000 copies/ml by the best routine Q-PCR. However, the initial RNA level is > 200,000 in over 99% of untreated patients with hepatitis C. Therefore, both methods are adequate for demonstration of the level of RNA in blood although the level measured by one technique does not necessarily correlate with the levels by other techniques. Generally, the Supra-quant assay correlates with the SA assay with the lower quartile of both assays being less than 2 million copies/ml. The Amplicor system tends to measure 1/5 to 1/10 lower numbers when expressed as copies/ml and was the first assay to be expressed in IU/ml. The determination to use an international standard expression as IU/ml was to allow comparison between methods. The lowest quartile using the amplicor system has a cut-off between 200,000 and 400,000 IU/ml in our laboratory, whereas the other methods have a cut-off of approximately 800,000 IU/ml. More work is required to make the different assay systems strictly comparable.

The value of the level of viral RNA is primarily for use in treatment. The baseline value is a major predictor of response to anticipated treatment. Patients who have RNA values in the lower quartile by any of the above techniques will have a greater response rate than those with higher values and some patients will need less treatment time. The cut-off for the lower quartile in the Schering studies was < 2 million copies per ml (Signal amplification and Supraquant). However this has been changed to IU/ml (a lower value) and the lower quartile by the Roche test (Amplicor) seems to have a cut-off somewhere between 250,000 and 400,000 IU/ml. Thus, a low viral load predicts a greater sustained response (SR) to therapy.

The rate of fall in the viral level over time allows measurement of viral kinetics in response to therapy. The second of the two phases correlates best with SR, although a very rapid fall in the first 24 hours has been reported as being almost as good. A rapid response indicates the greater likelihood of a SR. The rate of decline over the first months of therapy may help make the decision when to stop treatment due to a non-response. No change (or < 50% decrease) in viral level at 3-4 months identifies a patient who is unlikely to have a SR and treatment can be stopped. A continually falling level for the first few months can be helpful in encouraging a patient to continue therapy. A rising level after an initial fall is associated with non-response.

Screening for hepatitis C

The screening for hepatitis C depends on the setting. HCV antibody is adequate for most situations with abnormal liver tests although, eventually, a positive RNA must be demonstrated. However, even with abnormal liver tests, the HCV antibody may be falsely negative with high rates (20%) in the immune suppressed patient (ie, HIV or dialysis). The RNA is required in immune suppressed patients with ALT to exclude HCV.

The patients who should be screened are those at highest risk. This includes patients with a history of transfusions (particularly prior to 1980), multiple transfused hemophiliacs, HIV patients, patients who have shared needles during IV drug use even on only one occasion, patients with more than 2 sexual partners per year, and spouses of infected patients.

Natural history of hepatitis C

The hepatic inflammation caused by active hepatitis C in the liver produces most of the problems with hepatitis C by causing symptoms and progressive hepatic fibrosis (leading to cirrhosis). Progressive hepatic fibrosis may eventually result in cirrhosis, the major manifestations of advanced chronic liver disease (ascites, GI bleeding, renal failure, hepatic encephalopathy and infection) and predisposition to liver cancer (hepatocellular carcinoma – HCC). There can also be problems outside of the liver usually due to antibody combinations with viral components (immune complexes) or the unmasking of other liver problems such as porphyria cutana tarda (PCT) producing skin sensitivity to sun.

Symptoms

The symptoms in HCV are non-specific including fatigue, tiredness, decreased stamina and muscle aches and pains. However, < 20% of patients have symptoms when first evaluated and even these are usually mild. Many other diseases including depression produce fatigue and tiredness. Often the relationship of HCV to the symptoms is unclear and treatment that cures the HCV may not eliminate all symptoms. The severity of fatigue and tiredness is not related to the severity of the liver disease.

Hepatic Fibrosis

The single most important process in patients with liver disease is hepatic fibrogenesis leading to the progressive accumulation of scar tissue (fibrosis) in the liver. This scar tissue is similar to the scar that appears on the skin after a cut but is produced diffusely throughout the liver in response to diffuse inflammation. The liver inflammation is the stimulus or driving force for the progressive

build up of scar tissue. Inflammation can be estimated indirectly from the average level of AST and ALT in blood or directly from a liver biopsy. The scar tissue is called fibrosis early in the disease when only a little scar tissue is present, but cirrhosis when a large amount of scar tissue with regenerative nodules is present. Cirrhosis is an indication of far-advanced liver disease.

A large amount of hepatic scar tissue at the cirrhotic stage produces nearly all of the problems associated with chronic liver disease. The build-up of fibrosis causes portal hypertension (leading to a large spleen, ascites and predisposing to gastrointestinal bleeding from varices), a reduction in the functional mass of the liver (abnormal liver function tests and finally confusion due to liver disease), and infection. The definition of these clinical problems are:

Large spleen (hypersplenism) producing low white blood cell, red blood cell and platelet concentrations in blood

Ascites – the abnormal accumulation of fluid in the peritoneal cavity (area between the intra-abdominal organs) above the normal 25 cc usually to a volume of 2-15 liters (5-33 lbs) of fluid.

Varices – abnormally large veins usually in the esophagus and stomach that can bleed profusely and are a common cause of death

Spontaneous Bacterial Peritionitis (SBP) – infection in ascites

Hepatic Encephalopathy – confusion or coma due to liver disease predisposed by a reduced hepatic mass and abnormal veins around the liver (one type of which are varices) leading to delivery of high levels of toxins, such as ammonia, into blood.

Bacterial Infections – spontaneous sepsis, SBP, pneumonia, urinary tract infections and cellulitis

Renal Failure – a combination of events the most important of which is increased blood flow to the intestines usually highly significant after the mid-cirrhotic stage when ascites is present.

Variceal bleeding usually occurs at the cirrhotic stage (early to advanced), whereas ascites tends to occur at the mid-cirrhotic stage. SBP, renal failure, resistance to diuretics and hepatic encephalopathy (confusion) are found primarily at the terminal stage of cirrhosis.

The process of fibrogenesis in patients with HCV is slow with an average of 30 years from acquisition of infection to end stage liver disease. It takes over 30 years for half the patients to develop advanced liver disease. The rate of progression is very individual depending on age at infection, grade of inflammation, alcohol intake, and iron load. Patients with normal liver tests may not progress or may progress very slowly. An important part of the work-up is to assess the stage of liver disease by the complications that have occurred, physical exam, blood tests, and liver scans. Icteric sclera (yellowness in whites of eyes), certain skin manifestations, a firm liver, a large spleen, a low platelet count, reversal in the AST/ALT ratio, abnormal bilirubin, albumin and prothrombin time are associated with cirrhosis. However, the best direct assessment of hepatic fibrosis is the liver biopsy and best direct assessment of the functional hepatic mass is the quantitative liver-spleen scan. It is important for a patient to be followed over time for evidence of progression or improvement using all of these parameters.

The amount of fibrosis on biopsy can be semi-quantitated using a variety of scoring systems and serial biopsies can demonstrate progression. The most common is Knodells scoring system with fibrosis scores of 0, 1, 2 or 4. The Knodell system also gives a score to inflammation. The METAVIR scale is from 0 to 4 with 4 indicating cirrhosis. The modified Ishak score ranges from 0 to 8 with 7 and 8 degrees of cirrhosis. The Kanel scoring system is used at UCI with a scale for fibrosis from 0-2 and cirrhosis from 3-5. It is unclear which scoring system is best.

Only the METAVIR system has evaluated the rate of fibrosis. The average rate of progression is .133 units per year and the rate in an individual is directly proportional to the grade of inflammation. The rate is doubled by regular intake of two or more drinks per day.

Liver Cancer

The most important type of primary liver cancer (arising from the liver) is called hepatocellular carcinoma (HCC). Although cirrhosis of any type is associated with HCC, chronic hepatitis B, chronic hepatitis C and hemachromatosis have the highest incidence. Ninety five percent of tumors associated with HCV arise in patients with cirrhosis. The cirrhotic patient has 2% chance of developing HCC per year. Of patients who reach the cirrhotic stage, 20% will die of HCC. Screening has been shown to be useful for the early detection of HCC when the patient is without symptoms from the tumor and most tumors can be detected when they are < 5 cm in size, at a time when treatment is possible.

Extra-hepatic manifestations of Hepatitis C

Problems from HCV can occur outside of 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 extra-hepatic manifestations of HCV are due to immune complexes formed from viral proteins and anti-bodies in blood. Cryoglobulinemia is one type of immune complex causing a reddish rash (prominent on the 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 planas is another problem manifested by skin disease and mouth ulcers.

Treatment for hepatitis C

The goal of treatment is viral cure that for practical clinical purposes is defined as a sustained response (SR). A SR is defined as a negative HCV RNA by qualitative PCR during active treatment that remains negative by qualitative PCR 6 months after stopping therapy. However, a delayed relapse is possible within the next year in < 2% of patients. The rest of the patients are unlikely to have any further problems with HCV, although that does not entirely reverse liver disease that has reached the stage of cirrhosis or eliminate the possibility of HCC. However, progression of the liver disease is arrested, extra-hepatic disease is improved or eliminated, the likelihood of HCC is markedly reduced and symptoms due to HCV are relieved.

Patients who never become RNA negative during treatment are termed non-responders. Those who become RNA negative during treatment, but become RNA positive after stopping medication are said to have relapsed. Patients who become RNA negative during treatment, but become positive again while still on treatment are said to have a complete response with breakthrough. Patients with a complete response during treatment with subsequent breakthrough or relapse have a better response to retreatment than non-responders.

There are additional secondary benefits of treatment that may occur in the absence of viral cure (non-response or relapse). Ten percent of patients will have long-lasting biochemical improvement resulting in slower progression of the disease (although 30% of patients will have a biochemical relapse within 2 years). Also, there is evidence that interferon directly slows down the fibrotic process and this is sustained for a period of time after completion of treatment. Sometimes symptoms will permanently improve after treatment regardless of the viral response. Furthermore, the incidence of HCC decreases. The secondary benefits of treatment must be considered when deciding on treatment.

An SR requires interferon as part of the therapy. The initial rates of viral SR with interferon alpha-2a or 2b in naïve patients (those not previously treated) given in 3-5 million units three time a week (TIW) were 5-8% after 6 months of treatment and 10-12% after 1 year of treatment. There have been many improvements since these therapies were introduced in the late 1980s. Infergen is a more potent interferon introduced in the early 1990s. However, the most important advancements were the development of interferon treatment combined with ribavirin (Rebetron), pegylated interferons (given 1 time per week) and pegylated interferon plus ribavirin. Rebetron has an over-all SR of 35% in naïve patients, 10-15% in non-responders to interferon alpha 2a or b, and 50% in patients who relapse after interferon 2a or b treatment. Monotherapy with pegylated interferons in naïve patients is more convenient because of weekly therapy, but has a SR of 27-30% in naïve patients. Pegylated interferon plus ribavirin has a SR of 40-45% in naïve patients. Clearly, therapy has improved in the last 15 years.

The response rates to each of these therapies are determined by viral genotype and RNA level in blood by one of the quantitative tests. In patients with genotype 1, the SR rate to Rebetron is 28%, pegylated interferon monotherapy 25% and pegylated plus Ribavirin 30-35%. A viral level in the lowest quartile of untreated patients adds an additional 10-15% to each of these response rates. In patients with genotype 2 and 3, the response rate to Rebetron is 45-55%, pegylated interferon monotherapy 40-50% and pegylated plus Ribavirin 50-60%. In addition, a low viral titer adds an additional 10-15% SR to these percentages. A genotype 3 is the most responsive and, with a viral level in the lower quartile, may have a response rate in naïve patients as high as 80-85%. Cirrhosis decreases the response rate in each of these categories by 10%.

The length of treatment is generally 12 months for genotype 1 and as short as 6 months for the other genotypes. The initial viral level in the lower quartile, rate of fall in the RNA levels and time of first RNA negativity may affect the time of stopping treatment.

The outlook for patients with HCV has improved with more effective therapies. However, there is a cost in side effects. Nearly all patients have side effects initially that peak within the first 4-8 weeks. These problems include fatigue, tiredness, weakness, fever, rashes, and nausea. A major problem is with depression, anxiety and other psychiatric manifestations. They are common and increase the longer and higher the dose. Fortunately, anti-depressants are usually effective treatment. Ribavirin adds significantly to the symptoms in 10% of patients who may find the side effects intolerable. Patients treated with the combination of interferon and ribavirin stop medications more frequently. The side effect profile with the pegylated interferons is similar to the older products.

Suppression of the blood elements occurs with all interferon products and generally to the same degree. The pegylated interferons may have a greater suppression of the platelets. A lower white blood cell (WBC) concentration may predispose to infection particularly when the absolute polymorphonuclear (APMN) concentration is less than 500 cell/mm3 (medication is often reduced if the WBC is less than 750 cells/mm3). A low platelet count may predispose to bleeding when the platelet count is < 50,000 cells/mm3, but bleeding is uncommon unless platelet function is also inhibited such as when taking aspirin (inhibits platelet function for up to two weeks after one dose) or non-steroidal anti-inflammatory agents (Advil, Motrin, Aleve, etc) that inhibits platelet function to a much smaller degree and for a shorter time than aspirin (< 24-48 hours). The red blood cell concentration is only slightly depressed with interferons, but the addition of ribavirin to therapy causes hemolysis (destruction of red blood cells) with an additional average 20% decrease in red blood cell count. The ribavirin dose may be decreased if the hemoglobin falls below 10 gm%. Occasionally, a severe hemolytic anemia occurs rapidly, which is why blood tests are taken at two weeks after initiation of treatment. The maximal decreases in the blood elements have usually occurred by week 6-8 of treatment, and few patients require dose reduction because of this.

New Therapies for hepatitis C

New therapies that attempt viral cure still require interferons as the base. A new form of ribavirin (Levovirin) may improve the response to interferons without the side effect of hemolysis. The other side effects are likely to be the same. Other medications that are being studied as interferon enhancers are histamine antagonists and Cellcept.

Other new therapies have changed the strategy from viral cure to viral control. These are the anti-viral agents. Ribavirin was initially studied as an anti-viral agent, but had little effect on viral levels. Anti-virals have not yet lived up to their promise despite ongoing studies for about 10 years. These include anti-sense oligonucleotides and ribozyme inhibitors. None of these are commercially available, but may be available in studies. The suppression of viral replication occurs only as long as the medication is given. The suppression of the virus decreases viral induced hepatic damage. Prolonged low dose interferon may also allow long term suppression of the virus and, therefore, progression of the liver disease.

Lastly, the strategy may change further to control of the progression of the fibrosis with less focus on the viral levels or even decrease in inflammation. Anti-fibrotic agents have not been studied in detail in patients with HCV, probably because no really effective agent is available. However, interferon itself appears to be anti-fibrotic. It is possible that low dose maintenance interferon therapy may prevent progression of disease. This has become much more practical sense the development of pegylated interferons because the medication can be give once a week rather than more often. The National Institutes of Health (NIH) is supporting a trial of maintenance pegylated interferon in viral non-responders that should answer this question. Furthermore, it should answer the question of whether this occurs independently of viral suppression and improvement in inflammation.

Lifestyle interventions, etc.

The major life-style change is to stop drinking alcohol. This is most important when a person drinks almost daily and particularly when alcohol intake equals or exceeds an average of 2 drinks per day. In regular drinkers, abstinence is required since people usually return to their baseline-drinking pattern over time. The occasional drinker (< 1-2 drinks per week) may be allowed to maintain this pattern although it has not been shown to be entirely safe.

Fatty liver also predisposes to progressive fibrosis in patients with HCV. Fatty liver usually occurs in the setting of alcohol consumption or being > 50% above ideal body weight. Other predisposing factors to fatty liver include hyperlipidemia (increased blood triglycerides and cholesterol) and diabetes mellitis. Weight loss and good control of diabetes may decrease the rate of progression by improving the fatty liver.

Excess iron may accelerate the fibrotic process in patients with Hepatitid C.

HEPATITIS C REPORTING IN ORANGE COUNTY

Hildy Meyers, M.D., M.P.H.
Medical Director, Epidemiology & Assessment
Orange County Public Health

Hepatitis C virus (HCV) infection became a separately reportable condition in California in February 1996. Prior to that, it was included under Non-A, non-B (NANB) hepatitis. For reporting purposes, an acute case of hepatitis C is defined as a person with all of the following: 1) a positive anti-HCV antibody or HCV RNA, 2) a discrete onset of symptoms consistent with hepatitis, 3) elevated aminotransferase levels at least 2.5 times the upper limit of normal, and 4) no previous laboratory evidence of HCV infection.

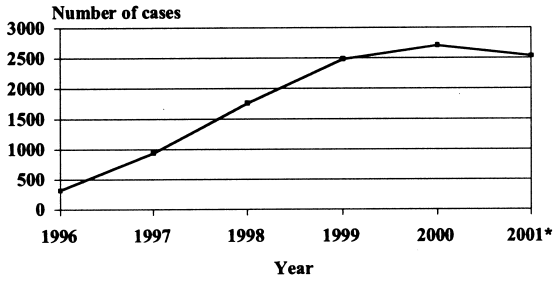
For reporting purposes, a case of chronic HCV infection is defined as a person with anti-HCV antibody or HCV RNA or a liver biopsy consistent with chronic HCV infection. Most cases of HCV infection reported to us do not specify acute or chronic and are counted as chronic cases.

When a case of acute HCV infection is reported to us, we attempt to contact the person and gather information on the possible source(s) of infection. We also provide education and information. For chronic HCV cases, we send information on HCV.

The number of cases of HCV reported to us has increased dramatically since reporting began in February 1996 (see Figure 1). In the year 2001, 2521 chronic and 10 acute cases were reported. 65% of cases were male and 35% were female.

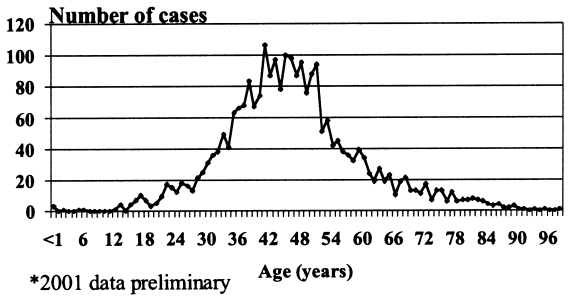
The number of cases reported is not a true reflection of current incidence of HCV infection in Orange County, as many people who were infected years ago have been tested (and reported) only recently. In addition, as many as one-fourth of persons who have anti-HCV antibody do not have active infection with virus—they have either cleared the virus from their body or the test itself was falsely positive.

Figure 1: Reported HCV Cases
Orange County



The Centers for Disease Control and Prevention (CDC) Sentinel Counties Study results indicate that there was a steep decline in new HCV infections after 1989. However, the large reservoir of chronic cases is of great concern. The median age of chronic HCV cases reported to us in the year 2001 was 45 years (see Figure 2).

Figure 2: Age of Reported Chronic HCV Cases, Orange County, 2001*



We look forward to helping to implementation of a Strategic Plan that will address this important public health problem.

PRIMARY PREVENTION

GOAL: Significantly decrease the number of people newly infected with hepatitis C using the most effective primary prevention strategies.

Definition of Primary Prevention

Primary prevention includes strategies and goals that will prevent uninfected persons from becoming infected.

The goal is to raise awareness and provide education related to hepatitis C prevention, harm reduction, and early identification and treatment for those at highest risk.

Current Prevention Efforts

- Blood bank screening
- Promotion of harm reduction strategies
- Education incorporated into substance abuse treatment programs
- Advisory Council on Hepatitis C

Strategies to Reduce Risk of Contracting Hepatitis C

- Use of culturally and linguistically appropriate public and professional educational programs
- Media campaigns
- Needle/syringe exchange programs
- Education of high risk groups
- Collaboration with existing providers (HIV, methadone, STD and substance abuse)

Who Must We Reach with Prevention Education?

1. Persons infected with hepatitis C

2. High-Risk Groups

- Injection drug users
- Persons with multiple-sex partners
- Incarcerated and paroled persons

3. Other Groups

- School teachers and students
- General public
- Persons who were ever on long-term dialysis
- Hemophiliacs or anyone else requiring treatment with clotting factors prior to 1987
- Women of childbearing age
- Immigrants from high-prevalence areas
- Persons with HIV infection
- Healthcare providers, including emergency medical and safety workers/others with blood exposure
- Recipients of transfusions, tissue or organ transplants prior to July 1992

Risk Reduction Objectives

- Educate staff, including risk reduction counselors, who work with clients at risk of HCV infection
- Increase access to drug treatment (number of inpatient beds, detoxification, social models)
- Collaborate in development of risk reduction programs for schools, including comprehensive health education curriculum
- Assure availability of multi-language and low literacy materials
- Reinforce infection control education
- Encourage policy makers to assess availability of clean syringes, support decriminalization for possession of syringes, and evaluate need for and advantages of needle/syringe exchange

Challenges to Prevention

- Educating infected individuals
- Knowledge and data to support need for programs
- Empowerment by persons infected and affected by hepatitis C
- Financial resources
- Culturally and linguistically sensitive materials
- Resistance to teach/promote sexual health
- Political support within community
- Public interest to support programs for high risk groups

OBJECTIVE #1

Create advisory body to explore need and advisability of expanding harm reduction interventions in Orange County

- Advisory Council will form a working committee to enlist supporters, identify obstacles and challenges, collect data, develop action plan, and implement action plan

OBJECTIVE #2

Conduct needs assessments and asset mapping

- Contact CDC for concepts
- Gather samples of working surveys
- Design needs assessment and asset mapping surveys
- Analyze data

OBJECTIVE #3

Develop and conduct educational programs for physicians and other health care providers by collaborating with identified experts and institutions (see also Professional Education and Training Goal)

OBJECTIVE #4

Form a professional advisory group that will identify experts in hepatitis C willing to be part of a local speakers bureau.

- Identify funding sources to offset or provide for costs of professional speaker's services, if necessary

OBJECTIVE #5

Implement a social marketing campaign

- Design
- Field test
- Implement
- Evaluate

OBJECTIVE #6

Identify partners for local public education outreach campaign, including programs that will raise awareness about hepatitis C and steps that may reduce the risk of acquiring or transmitting the disease.

OBJECTIVE #7

Develop educational programs for schools

- Explore model programs with Department of Education
- Partner with other organizations
- Assure integration of hepatitis C prevention information into health curricula
- Involve school nurses

OBJECTIVE #8

Educate hepatitis C infected persons to prevent transmission to others

SECONDARY PREVENTION

GOAL: Identify people infected with hepatitis C and offer accessible and affordable case management and treatment services to prevent or limit the progression and complications of hepatitis C

Definition of Secondary Prevention

Secondary prevention is defined as strategies used to identify, counsel and test individuals most likely to be infected with hepatitis C in order to prevent progression of the disease and improve the health of those who are infected.

Secondary prevention can reduce the risks for chronic liver disease by identifying infected persons as early as possible through diagnostic testing, and providing appropriate counseling and medical treatment. Appropriate care and treatment will minimize liver damage, encourage patients to engage in actions to improve their health and well being, and reduce risk of transmitting hepatitis C to others.

It is important that health care providers give their patients information that includes the following:

- Risk reduction in preventing disease transmission and progression
- Treatment options and consequences
- Importance of immunization for hepatitis A and hepatitis B

Current Prevention Efforts

- Vaccination against hepatitis A and B
- Screenings (blood donors)
- Education
- Passive surveillance
- Support groups
- Substance abuse treatment programs
- Train-the-trainer programs

CDC Recommendations for Routine Screening

- People who injected drugs (even once or a few times, many years ago and who do not consider themselves drug users)
- People who received clotting factors before 1987 or who have ever received hemodialysis
- Recipients of transfusions or organ transplants (before July 1992)
- Health-care workers or emergency workers after exposure to blood
- Children born to HCV-positive women
- Persons who are HIV-positive

Other Persons Who May Benefit from Screening

- War veterans
- Immigrants from countries with high-prevalence of hepatitis C
- Persons who have served time in prisons

Persons for Whom Routine Screening is not Generally Recommended at This Time (*CDC MMWR Report October 1998*):

- Recipients of transplanted tissue (e.g., corneal, musculoskeletal, skin, ova, sperm)
- Intranasal cocaine and other noninjecting, illegal drug users
- Persons with a history of tattooing or body piercing
- Persons with a history of multiple sex partners or sexually-transmitted diseases
- Long-term, steady sex partners of HCV-positive persons

Challenges to Secondary Prevention

The Advisory Council on Hepatitis C for Orange County identified several challenges to secondary prevention:

- Inadequate medical care for uninsured and underinsured persons, making it more difficult to treat individuals who may be infected with hepatitis C
- Outreach efforts may promote more demand on already inadequate services.
- Lack of consistent funding to develop new programs and sustain ongoing programs. Proposing new programs and services will require identification of funding sources and financial investment.
- Society will need to understand the importance of supporting efforts and providing opportunities for mobilization, advocacy, and empowerment of the affected community.

OBJECTIVE #1:

Design surveillance and monitoring system to ensure proper case management of HCV-positive persons

- Advocate for staff position at County of Orange Health Care Agency

OBJECTIVE #2:

Increase the number of high-risk individuals who are screened and counseled

- Identify existing models
- Identify resources for referral

OBJECTIVE #3:

Disseminate information for effective infection management

OBJECTIVE #4:

Develop, update and disseminate clinical trials information

- Public Health Bulletin
- Web site links
- Federal/State information line

OBJECTIVE #5:

Promote and improve access to medical care

- Advocate for funding for screening, treatment and prevention
- Identify medical resources and gap areas
- Build community capacity to provide a continuum of care to include medical services that are culturally appropriate
- Link persons to available benefits and services
- Support implementation of a national health care system for all

OBJECTIVE #6:

Assist patients in addressing basic psychosocial needs

OBJECTIVE #7:

Revise notification information sent by the County of Orange to hepatitis C-positive persons.

OBJECTIVE #8:

Promote organ donor awareness throughout the county

OBJECTIVE #9:

Develop/provide educational resources on liver transplantation resources and procedures

PROFESSIONAL EDUCATION AND TRAINING

GOAL: Provide education and training in hepatitis C for health care professionals, including students and trainees, health care and other program volunteers, staff of alcohol and drug treatment programs, outreach workers, staff of local health agencies such as STD and substance abuse services, management and front-line workers in correctional facilities, staff of organizations that work with the homeless, and providers who serve veterans.

Current Education and Training Efforts

- Focused conferences and breakout sessions on hepatitis C in other related conferences have been available in Orange County and beyond
- Industry has provided sponsored educational programs targeted at providers
- Continuing education of medical staff exists and is ongoing in some settings
- Training has been made available through professional associations
- Targeted education by existing groups, including grassroots groups, has been available to service providers
- Internet education for professionals

Overview of Professional Education

The Centers for Disease Control and Prevention recommends that HCV-specific information be provided to infected persons and individuals at risk by trained personnel in public and private health-care settings. Health education materials should include general information about HCV infection, risk factors for infection, transmission, disease progression, and treatment; and detailed prevention messages appropriate for the population being served. Written materials might also include information about community resources available for professional education and training.

Why is it important to prioritize training and education?

- Proper training of providers is essential to case management of those infected with hepatitis C
- The majority of professionals may not understand the magnitude of the problem and its association with the health care systems and medical care costs
- It is important to be able to differentiate between the hepatitis viruses and HIV
- The absence of programs and public media campaigns in Orange County make it difficult to motivate professionals
- Many physicians are not current on the disease elements and therapies, including risk assessment screening
- Support services personnel, such as counselors, nurses, and public financial assistance providers, are lacking in information about hepatitis C
- Knowledge about hepatitis C will help reduce the number of new cases of the disease, increase the numbers who are screened, and should be effective in supporting the management of disease

Challenges to Professional Education and Training

Challenges to effective professional education and training might include:

- Opportunities for providers to attend programs
- Financial limitations of individuals and institutions to pay for education and training
- Ability to serve the needs of professional providers
- Establishing various educational curriculums and strategies to serve the needs of professional provider groups
- Identifying and assisting professionals serving ethnically diverse and hard to reach populations

OBJECTIVE #1:

Establish a professional education committee

OBJECTIVE #2:

Assure availability of focused conferences on hepatitis C and breakout sessions on the virus at related health conferences

- Promote continuing education of all medical staff
- Identify professional organizations and provide training
- Targeted education to service providers
- Identify quality internet resources and make information available

OBJECTIVE #3:

Standardize curriculum by populations to be served with education and training

- Establish a speaker's bureau
- Collaborate with and create partnerships with professional organizations
- Develop curriculum and culturally appropriate supplemental materials

OBJECTIVE #4:

Establish a communication system for professionals

- Email system
- Regular meetings
- Newsletter

PUBLIC EDUCATION AND TRAINING

GOAL: Provide education and training about hepatitis C as a comprehensive public health campaign to reach a general audience of people in Orange County. The campaign shall reach those who are not infected, those who may be at risk, and those with hepatitis C.

Current Education and Training Efforts

- Community education programs sponsored by local nonprofit organizations targeted at those diagnosed with hepatitis C
- Support groups
- Street education
- Internet education and information, including support environments
- Printed materials about hepatitis C and hepatitis C prevention

Overview of Public Education

Health education materials should include general information about HCV infection, risk factors for infection, transmission, disease progression, and treatment; and detailed prevention messages appropriate for the population being served. Written materials might also include information about community resources available for general public information, as well as information and programs for those people diagnosed with hepatitis C.

According to the State of California's Strategic Plan, a campaign should raise awareness about hepatitis C and outline steps that can be taken to reduce the risk of acquiring or transmitting the disease. Campaigns will take into consideration a coordination of both Primary and Secondary Prevention components and objectives. (See Primary and Secondary components)

It is important that we prioritize public education and training for many reasons

- Proper education of those infected with hepatitis C tends to empower patients to have better self-advocacy skills to manage their health
- Most people infected with hepatitis C have not yet been identified through screening and testing
- It is important to be able to differentiate between the hepatitis viruses and HIV
- Knowledge about hepatitis C will help reduce the number of new cases of the disease, increase the numbers who are screened, and should be effective in supporting the management of disease

Challenges to Public Education

Challenges to effective public education and training might include:

- Communication vehicles to reach all audiences to inform about programs
- Financial limitations of individuals to pay for education
- Ability to serve the various needs of patients and the general public
- Need for consistent messages that are culturally and linguistically appropriate
- Stigma associated with risk factors and transmission of hepatitis C
- Ability to reach ethnically diverse populations

OBJECTIVE #1:

Establish a public education committee

OBJECTIVE #2:

Assure availability of focused conferences on hepatitis

- Promote education of all patients
- Identify and create partnerships with professional organizations
- Identify quality resources and make information available

OBJECTIVE #3:

Standardize curriculum by populations to be served with education and training

- Utilize a developed speakers bureau (refer to Professional Education component)
- Develop consistent messages for the community and disseminate materials accordingly
- Develop culturally and linguistically appropriate materials

OBJECTIVE #4:

Establish a communication system for the community

- Web site and contact availability
- Improved broadcast of support groups and community meetings
- Development of a media campaign

OBJECTIVE #5:

Collaborate with private and public schools to include appropriate curriculum on liver wellness and disease

- Identify and update HIV/AIDS and sexual health education curricula to include a component on hepatitis C
- Identify or develop video based materials

SURVEILLANCE

GOAL: Generate accurate data on hepatitis C that will direct and support the components of the strategic plan and assist the County of Orange in obtaining funding to address the problems relating to hepatitis C

Definition of Surveillance

Surveillance is the ongoing and systematic collection, analysis, and interpretation of health data for the purposes of planning, implementing and evaluating public health programs.

According to the Centers for Disease Control and Prevention, surveillance of acute hepatitis C provides the information necessary for determining incidence trends, changing patterns of transmission and persons at highest risk for infection. In addition, surveillance for new cases provides the best means to evaluate effectiveness of prevention efforts and to identify missed opportunities for prevention.

For chronic hepatitis C-related liver disease, surveillance can provide information to measure the burden of disease, determine natural history and risk factors, and evaluate the effect of therapeutic and prevention measures on incidence and severity of disease.

Current Surveillance Efforts

- Maintain electronic records (registry) of all cases reported to the County of Orange
- Interview acute cases of hepatitis C

Challenges to Surveillance

- HCV-infected persons may not be tested because neither they nor their physicians recognize that they have risk factors for infection
- Many physicians do not understand that it is their responsibility to report certain communicable diseases such as hepatitis C
- It is difficult to distinguish among acute, chronic or resolved infection when a hepatitis C case is reported. This most often occurs because insufficient information is reported (e.g., only a lab report of a positive HCV antibody tests is received, no confirmatory testing is reported, no physician report is received)
- There is currently no funded staff position to manage or supervise hepatitis C surveillance in Orange County
- Lack of referral resources

OBJECTIVE #1

Educate physicians on whom to screen and current reporting requirements

- Distinguish between acute and chronic hepatitis C

OBJECTIVE #2

Request additional staffing for the HCA/Disease Control & Epidemiology Division in Orange County to improve data collection

OBJECTIVE #3

Collaborate with the California Department of Health Services to develop a standardized case definition and surveillance form

OBJECTIVE #4

Analyze data received from reported cases of hepatitis C in order to determine disease incidence and trends, risk factors and patterns of disease transmission, and disease burden in Orange County

PUBLIC AND PATIENT ADVOCACY

GOAL: Provide an environment that encourages both infected and affected individuals to actively participate in public policy and educational activities that increase knowledge, funding, research and care for hepatitis C.

Definition of Advocacy

Advocacy is the act or pleading of a process or a cause or idea. Advocates are needed at many levels to make positive strides in health care management. Patient Advocates are those infected with hepatitis C. Public Advocates are other people working on the cause, including legislators, counselors, media, family members and friends.

For many years, advocacy has been a positive presence in health issues. Patient advocates have impacted health care, including education and awareness, and have typically been inspirational for health planning and wellness of those infected by disease.

Current Advocacy Efforts

- Support groups which advocate for education, support and hope for those infected and affected by hepatitis C
- Organizations working in the streets to screen and educate those at high-risk for infection
- Identified patient advocates and organizations
- Media has provided the vehicle in Orange County on topics relating to hepatitis C prevention and human interest stories

Challenges to Advocacy

- Most patients are chronically infected and experience fatigue and other side effects of liver disease
- Diverse community, difficult to enlist enough people to serve the needs of Orange County
- Stigma associated with risk factors and transmission of hepatitis C that reduce patient and public advocacy participants
- Need to develop a better communication system to provide a vehicle for advocates to enlist and stay empowered to make a difference

OBJECTIVE #1

Form a committee of interested people for the purpose of developing and implementing effective strategies to advocate for the hepatitis C community and individual hepatitis C patients

OBJECTIVE #2

Expand web site resources to include advocacy projects and opportunities for people in Orange County

OBJECTIVE #3

Increase awareness and knowledge of policy makers regarding hepatitis C

- Teach those interested about the importance of legislative involvement
- Collaborate with existing organizations and groups to educate elected officials
- Encourage letter writing campaigns

OBJECTIVE #4

Seek media opportunities to increase awareness and encourage participation in advocacy activities

OBJECTIVE #5

Create a system to monitor the effectiveness of the strategies

MEDICAL MANAGEMENT AND REHABILITATION

GOAL: Slow the progression of hepatitis C, engage the patient and his or her family in disease management and rehabilitation, improve long-term management of hepatitis C, and improve the affected individual's quality of life.

Definition of Medical Management

Medical management is the process of providing a diagnosis and medical plan for each patient chronically infected with hepatitis C that would include drug and alcohol use, problem and resolution planning, care for dependencies, treatment of disease, and counseling.

Current Medical Management Efforts

At the present time, most hepatitis C patients are being seen by private practitioners in the private practice setting. Many clients are seen by providers through special clinics at the University of California Irvine or special clinics through managed care institutions such as Kaiser Permanente, and many veterans are seen at the Long Beach facility or through its satellite clinics in Orange County.

Many physicians are doing liver biopsies to determine staging and disease progress which is helpful to both the physician and patient in health planning.

Some of the risk agencies, such as those serving persons living with HIV or substance use, offer special education and counseling which they started providing based on demand (high incidence of disease in their respective clients).

The first patient and family member support group started in 1997, with a second group serving south county in 2000. These support groups serve to provide access to education and psychosocial support to those infected and affected by hepatitis C.

Hepatitis festivals were held at Irvine Regional Park (1997, 1998, 2000) to help promote awareness of the disease. These events were covered by local media and were attended by patients living in Orange County and beyond.

In 1999, a national organization called Hepatitis Foundation International conducted a program on hepatitis C for the general public and hosted a morning program for public health and support group leaders as a sharing and roundtable session.

In 2000, a luncheon program was held for patients entitled Hepatitis C Advancing Liver Disease. Over 200 people attended the event to learn more about self-advocacy, end stage liver disease options and liver transplantation progress.

Education programs have been made available to physicians, primarily through the support of pharmaceutical companies for the primary purpose of education about treatment and disease management options.

Public health and occupational nurses, and school officials have been part of special education efforts specifically related to hepatitis C.

The County of Orange and UC Irvine Medical Center have an annual HIV program which has included a segment on hepatitis C to help educate those providing for and living with coinfection.

Clinical trials have been available through the University of California Irvine and private physicians as a way to offer opportunities to try potential therapies and/or low cost/no cost treatment.

Who must be reached for Medical Management and Rehabilitation?

It will be important to develop a plan that looks at several strategies to address populations to be served, populations serving, and appropriate access.

- Medical providers
- Others serving patients and family members

Quality of Life

As with many long-term illnesses, hepatitis C can cause a significant amount of stress on the patient and those around him. Some patients will not have solid support systems, while others lack the financial status to have needed care. We will find patients still struggling with substance or alcohol abuse while living with advancing liver disease.

The need to promote support and education and to identify or build appropriate training systems in this area will be important.

Standards of Care

The development of clear standards of care would be helpful in the management of hepatitis C. Early and effective treatment of hepatitis C may reduce the viral load, may eliminate the disease, informs patient about risks, and may limit the possibility that the virus will be transmitted further.

Using standards and having access to medical management through qualified providers can reduce overall the morbidity and mortality of hepatitis C.

Challenges to Medical Management

- Education of medical providers
- Lack of a clear standard of care
- Access to medical care and support systems
- Funding for ongoing medical education programs
- Ineffective outreach at present to serve those persons of different ethnicity, including linguistic barriers

OBJECTIVE #1

Identify education and training opportunities and support promotion of events on long-term clinical management to physicians, nurse practitioners, physician assistants, registered nurses, social workers, drug and alcohol counselors, and allied health professionals.

- Promote an annual program for providers and public health
- Calendar and make available information from recognized conferences such as American Association for the Study of Liver Diseases (AASLD), Digestive Disease Week (DDW), and through organizations such as the Department of Health Services (DHS) and the National Institutes of Health (NIH)

OBJECTIVE #2

Assign or seek volunteer committee who will work with the University of California Irvine to develop curriculum to train physicians.

- Mentoring program to train providers
- Grand rounds
- Continuing education units for programs

OBJECTIVE #3

Develop consistent messages for Orange County

- Education publications that serve as resources for Orange County residents
- Insurance and access information, including Medical Service for Indigents (MSI), MediCal, Medicare, private insurance, pharmaceutical industry sponsored programs, clinical trials
- Identify messages that encourage, support and train concept of patient empowerment for health

OBJECTIVE #4:

Identify interested groups or individuals that will keep a pulse on health care legislation and who will support or promote community involvement in policy changes that would insure continued medical coverage for hepatitis C patients and access to private insurance without cost penalties.

GLOSSARY OF TERMS

Acute hepatitis C: Newly acquired hepatitis C virus, sometimes but not always unaccompanied by symptoms. Acute infection with hepatitis C is often very mild, lasts less than 6 months (often less than 12 weeks) and goes unnoticed by most people.

Advocate: A person, persons, or organization pleading a process or a cause or idea.

AIDS: Acquired Immune Deficiency Syndrome

Alanine aminotransferase (ALT): A protein which, when found in the blood in elevated quantities, generally indicates liver damage.

Antibody test: Initial blood test that looks for antibodies to the virus and not for the virus itself. When positive, the test represents prior exposure to the virus. Additional confirmatory tests are recommended.

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 C: A stage of hepatitis C that usually begins about six months after initial infection and results in liver inflammation; occurs when the disease does not clear up or resolve spontaneously, often leading to permanent liver damage.

Cirrhosis: Extensive and permanent scarring of the liver. Cirrhosis interferes with the normal functioning of the liver.

Clinical trials: Research procedures and protocols that test the safety and efficacy of experimental medicines on groups of people in order to identify who may benefit from a specific drug or treatment.

Co-infection: A general term referring to infection with two or more infectious agents. Hepatitis C co-infection refers to infection with hepatitis C and another blood-borne virus such as HIV and/or hepatitis B.

Combination therapy: The use of two or more types of treatment in combination. In hepatitis C treatment, this term currently refers to a combination of drugs called interferon and ribavirin.

Complementary therapies: The various systems of healing that are not regarded as part of orthodox treatment by the medical profession. These therapies are not FDA approved. Sometimes these therapies are used by patients to reduce symptoms of disease or therapy.

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.

Epidemiology: The study of the distribution and determinants of health-related states or events (such as likely routes of transmission and trends in disease occurrence) in specified populations, and the application of this knowledge to deal with health problems.

False negative result: Incorrect result of test or procedure that indicates the absence of a condition or infection, when in fact the condition or infection does exist.

Fibrosis: Formation of scar tissue on the surface of the liver to replace normal tissue lost through injury or infection.

Gastroenterologist: A physician whose primary interests and experience involves the liver and intestines. Such a physician may be board certified in gastroenterology. The primary interest of most gastroenterologists is the intestines and in procedures that investigates intestinal disease.

Genotype: A term used to describe the specific genetic structure of hepatitis C. The ten identified genotypes are believed to be closely related in their genetic make-up, but differ sufficiently that each genotype causes different immune responses and responses to treatment.

Goal: Long-range preference statement of what the Advisory Council hopes to accomplish over time. More broadly stated than objectives, goals are impact and outcome oriented. The goal summarizes the plan to address problems within a given area as well as the anticipated results of the strategic actions.

Harm reduction: harm reduction aims to reduce the harm associated with potentially risky activities, rather than preventing people from performing those activities. Harm reduction incorporates a spectrum of approaches from safer use, to managed use, to abstinence. Clean needle and syringe exchange programs are examples of harm reduction.

Hepatitis: A general term meaning inflammation of the liver.

Hepatitis A virus (HAV): An RNA virus that infects the liver causing limited acute disease. It is most often transmitted through fecal-oral contact. There is no chronic infection with HAV. There is a highly effective vaccination against hepatitis A available.

GLOSSARY OF TERMS

Hepatitis B virus (HBV): A DNA virus that infects the liver causing acute disease and/or chronic liver disease. It is transmitted through blood, sexual contact, and perinatally (from mothers to infants). It can result in chronic liver disease, including cirrhosis and liver cancer. A vaccine against hepatitis B is available. Groups at high risk of acquiring hepatitis B include injecting drug users and men who have sex with men.

Hepatitis C Virus (HCV): An RNA virus that infects the liver causing relative acute disease, but frequent chronic liver disease. The virus enters the body through direct blood exposure and attacks cells in the liver, while often going undetected for many years. Hepatitis C can result in scarring of the liver (cirrhosis), liver cancer, and death. There is no vaccine for hepatitis C.

Hepatologist: A physician whose primary interest and experience is liver diseases. The physician is usually board certified in internal medicine and may be a gastroenterologist.

Human Immunodeficiency Virus (HIV): A family of viruses that results in the Acquired Immune Deficiency Syndrome (AIDS).

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

Indeterminate: The result of antibody test that is neither positive or negative.

Interferon: A genetically-engineered product used to treat hepatitis B and C and other viral infections.

Liver biopsy: A clinical procedure in which a small piece of the liver is removed. It is used to assess the health of the liver.

Mission: The fundamental reason or purpose for the existence of the Hepatitis C Strategic Plan. The mission statement expresses what Orange County wants to achieve in the long run by creating and implementing the Plan.

Natural history: The natural history of a disease is defined as its progression in the absence of any medical treatment or other intervention over a designated period of time.

Needlestick injury: Refers to an injury with a needle. Term is most commonly used in a healthcare setting.

Non-A, non-B hepatitis: Prior to 1989, this term was used to describe unexplained liver inflammation that was not caused by either hepatitis A or hepatitis B. It is now thought that most of the hepatitis C cases were once labeled non-A, non-B hepatitis.

Objective: A specific statement of a measurable amount of progress toward 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. The Orange County Advisory Council on Hepatitis C decided not to time-bound its objectives in terms of dates/years, but to assign a priority sequence that would be more realistic in the absence of funding at the present time and the overwhelming need to address many objectives.

Pegylated interferon: New interferons which are considered long-acting and slow release, administered once a week to treat hepatitis C. In combination with ribavirin, this therapy is considered the most effective treatment available at the present time.

Percutaneous: A procedure performed through the skin. Example in reference to an exposure to hepatitis C, a percutaneous exposure occurs when potentially infected blood enters the skin through a needlestick.

Polymerase chain reaction (PCR): A laboratory test (blood draw) which detects the presence or absence of the actual virus and/or the level of virus present in the blood (viral load). The PCR test is more commonly used today as the confirmatory test for hepatitis C.

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. As it relates to hepatitis C, primary prevention involves those strategies used to reduce the risk of contracting hepatitis C.

Ribavirin: An anti-virus oral drug often used in combination with interferon to treat hepatitis C. Ribavirin is ineffective when used alone.

Secondary prevention: Strategies used to identify, counsel, and test individuals most likely infected with hepatitis C (or other infectious diseases) and to provide them with appropriate medical and case management to prevent progression of the disease and improve health.

GLOSSARY OF TERMS

Sexually transmitted disease (STD): An infection transmitted through sexual contact. Examples include chlamydia, gonorrhea, or HIV.

Social marketing: the application of commercial marketing and communication principles to public initiatives/programs, in order to achieve social goals through behavior change. It is a much broader concept than one used in an awareness campaign.

Surveillance: Procedures used in public health to monitor disease incidence, prevalence and trends, and the effectiveness of prevention strategies.

Sustained response: This is a term which refers to the elimination of the hepatitis C virus following treatment. Current research suggests that if a person has a sustained response for 6 months after a course of therapy (no presence of virus as determined by a sensitive viral blood test), there is a good chance that the response will last indefinitely.

Vaccine: A substance that stimulates an immune response and renders a person immune to a particular infection. There is no vaccine for hepatitis C. There are vaccines available for hepatitis A and hepatitis B.

Vision: The collective sense of where the Orange County hepatitis C community wants to be in the next few years in prevention and management, and why. The Advisory Council will reconvene annually to access the strategic plan and monitor its work and gaps.

Special appreciation to the following individuals and organizations for their contribution to this glossary as reference resources and writers:

Australian Institute for Primary Care
- National Hepatitis C Resource Manual 2001

Dr. John Hoefs
University of California
Irvine, CA

Joseph Vargas
Orange County Health Care Agency, CA

Carol Craig
California Hepatitis C Resource Center, CA

Department of Health Services
State of California Strategic Plan

Orange County Health Care Agency

ORANGE COUNTY RESOURCES

EDUCATION AND SUPPORT

California Hepatitis C Resource Center/
Back to Life (A Tides Center Project)
949-654-4251
Toll Free: 1-888-85LIVER
Email: BacktoLife@emailaccount.com
Web Site: www.hepcCalifornia.org
The non-profit Orange County organization provides public awareness, education, support and hope for those infected and affected by hepatitis C. The program provides community education programs, support systems and groups, and training programs. Back to Life is the founder of the California Hepatitis C Resource Center and is the host of the Advisory Council on Hepatitis C for Orange County.

REACH
714-834-7926
Toll Free: 1-866-33REACH
The Risk-reduction Education and Community Health (REACH) Program encourages persons to improve their physical and emotional health, regardless of their circumstances or lifestyle. The program provides a safe and confidential environment for substance abusers and their sexual and/or needle sharing partners. REACH provides case management services, street outreach, educational presentations, HIV/HBV/Syphilis screening, and life skills workshops to persons at high-risk of HIV.

Additionally, REACH provides HCV education, HCV antibody testing, literature, safer injection information and bleach kits, and safer-sex kits throughout Orange County. These services are provided through street outreach, individual counseling, and formal presentations to high-risk individuals.

Saddleback Valley Community Church
Support Ministry, Hepatitis C Support Group
949-830-6873
Email: GSLADEK@MTSCNC.COM
The purpose of the support group is to support and educate hepatitis C sufferers in a safe and respectful environment. Offer helpful information that inspires and informs the hepatitis C patient and their families to grow in the understanding of their disease. To also find hope and encouragement by meeting regularly with other sufferers and learning from their past, dealing with the present, plus chartering their future. Persevering each day by leaning on God's power and promises so that we stay strong in coping with our affliction.

SCREENING

Special Diseases (STD/HIV/AIDS) Clinic
1725 W. 17th Street, Santa Ana, CA 92706
Information: (714) 834-8592
http://www.oc.ca.gov/hca/public/special_diseases/index.htm
This public health clinic provides free testing and treatment for sexually transmitted diseases. This is a walk-in clinic. There are no appointments.

REACH
714-834-7926
Toll Free: 1-866-33REACH
The Risk-reduction Education and Community Health (REACH) Program encourages persons to improve their physical and emotional health, regardless of their circumstances or lifestyle. The program provides a safe and confidential environment for substance abusers and their sexual and/or needle sharing partners. REACH provides case management services, street outreach, educational presentations, HIV/HBV/Syphilis screening, and life skills workshops to persons at high-risk of HIV.

Additionally, REACH provides HCV education, HCV antibody testing, literature, safer injection information and bleach kits, and safer-sex kits throughout Orange County. These services are provided through street outreach, individual counseling, and formal presentations to high-risk individuals.

OTHER RESOURCES

AIDS Services Foundation of Orange County
HIV Education, Care and Advocacy
949-809-5705
ASF provides care, education, and advocacy services to men, women and children affected by HIV disease and works to prevent its spread. Other objectives include design of services that are driven by the needs of clients which help them maximize the benefits of medical care, increase self-sufficiency, improve quality of life, and prevent the spread of HIV.

Access includes benefits counseling; chemical dependency counseling; family and children's programs; emergency financial assistance; food pantry; health assessments; treatment education; wellness services; home care; housing services; life skills and back to work services; mental health counseling; support groups; pastoral care; public policy information; recreation opportunities and transportation to medical and counseling appointments.

In 2000, 1,317 clients, their friends and families, and thousands more, were served in Orange County through the ASF prevention education outreach program.

Mariposa Women's Center
812 Town & Country Road
Orange, CA
714-547-6494
The Center is a non-profit agency founded in 1977 and funded in part by the Orange County Health Care Agency Drug and Alcohol Program. The primary objective of Mariposa is to provide a support and resource center for women whose lives are touched by the disease of alcoholism or other drug addictions. Mariposa's programs emphasize education and prevention.

Celebrate Recovery
Saddleback Church
1 Saddleback Parkway
Lake Forest, CA 92630
949-609-8305
email: CelebrateRecovery@saddleback.com
website: www.CelebrateRecovery.com
Celebrate Recovery meets every Friday night at 7:00 P.M. on the campus of Saddleback Church. There are groups for may different hurts, habits, and hang-ups. There are also meetings on Monday, Tuesday, and Saturday.

Narcotics Anonymous Orange County 714-776-8581
Narcotics Anonymous South Orange County 949-661-6183
Alcoholics Anonymous Orange County 714-773-4357

COUNTY OF ORANGE HEALTH CARE AGENCY
Public Health Services

EPIDEMIOLOGY & ASSESSMENT
Information: (714) 834-8180
http://www.oc.ca.gov/hca/public/cdce.htm
Epidemiology & Assessment (EA) investigates individual cases and outbreaks of specific communicable diseases to prevent their spread. EA also monitors and analyzes trends in these diseases, including Hepatitis C; compiles statistics; and provides information to doctors, hospitals, the public, and news media. Health care providers are required to report certain communicable diseases, including hepatitis C virus infection, to EA. Persons reported to EA with hepatitis C are given information about the disease and resources for more information and community support.

Special Diseases (STD/HIV/AIDS) Clinic
1725 W. 17th Street, Santa Ana, CA 92706
Information: (714) 834-8592
http://www.oc.ca.gov/hca/public/special_diseases/index.htm
This public health clinic provides free testing and treatment for sexually transmitted diseases. This is a walk-in clinic. There are no appointments.

HIV Clinic
Information: (714) 834-7991
Provides medical care for HIV and related conditions to uninsured persons. Services include medical care and early intervention services, such as case management, psycho-social assistance financial counseling, health education and risk reduction information. Psycho-social and support services may also be provided for underinsured persons.

HIV (AIDS) Testing Sites
Information: (714) 834-8192
http://www.oc.ca.gov/hca/public/hiv/testing.htm
Provide free anonymous or confidential testing for HIV antibodies, counseling, and referrals.

HIV Planning and Coordination
Information: (714) 834-8711
http://www.oc.ca.gov/hca/public/hiv/index.htm
Seeks to prevent the transmission of HIV, to encourage early intervention for those already infected, and to ensure that persons living HIV have access to needed health care and services. Staff coordinate HIV/AIDS prevention, care, treatment, and other support services. They monitor agency programs and community-based organizations receiving federal and State HIV/AIDS funding grants and subcontracts for services. They coordinate HIV/AIDS planning/advisory bdies in the community, including the HIV Prevention Planning Council and the HIV Prevention Planning Committee.

HEALTH PROMOTION
Disease Control Health Education (DCHE)
Information: (714) 834-8309
Provides materials and programs to assist patients, providers, and the community in understanding and preventing STDs, HIV/AIDS and Tuberculosis. Health educators and public health nurses provide patient education, as well as technical assistance and support to schools, colleges, youth groups, churches and other community-based organizations interested in health promotion and primary prevention.

Other Health Promotion Services:
Information: (714) 834-2228
http://www.oc.ca.gov/hca/directory/directory.htm
Consultation and technical assistance related to program planning, curriculum development, implementation, data collection, program evaluation and coalition building on a variety of health issues, including chronic disease and injury prevention (CDIP), sudden infant death syndrome (SIDS), breast cancer, tobacco use prevention program (TUPP), and alcohol and drug education teams (ADEPT). Multiethnic staff are available to provide health education services.

STATE AND NATIONAL RESOURCES

This is a partial list of State and National resources on hepatitis C. Note for patients: always include your health care provider as your primary resource on your health care if you are a patient. All information you identify as a resource should be shared with your medical provider before making any changes to your health care plans.

American Association for the Study of Liver Diseases (AASLD)
1729 King Street, Suite 100
Alexandria, VA 22314-2720
703-299-966
http://www.aasld.org

American College of Gastroenteroloy (ACG)
4900 B South 31st Street
Arlington, VA 22206
703-820-7400
http://www.scg.gi.org

American Liver Foundation (ALF)
75 Maiden Lane, Suite 603
New York, NY 10038-4810
800-465-4837
http://www.liverfoundation.org

California Hepatitis C Resource Center
14252 Culver Drive, A526
Irvine, CA 92604
949-654-4250
http://www.hepCCalifornia.org

Centers for Disease Control and Prevention (CDC), Hepatitis Branch; Mailstop G-37
1600 Clifton Toad N.E.
Atlanta, Georgia 30333
888-443-7232
http://www.cdc.gov/ncidod/diseases/hepatitis/c/

Digestive Health Initiative
7910 Woodmont Avenue, Suite 700
Bethesda, MD 20814
800-668-5237
http://www.gastro.org

Hep C Connection
1177 Grant Street, Suite 200
Denver, CO 80203
800-522-4372
http://www.hepc-connection.org

Hepatitis Foundation International
30 Sunrise Terrace
Cedar Grove, NJ 07009-1423
800-891-0707
http://www.hepfi.org

Immunization Action Coalition (IAC) Hepatitis B Coalition
1573 Selby Avenue
St. Paul, MN 55104
651-647-9009
http://www.immunize.org

National Digestive Diseases Information Clearinghouse (NDDIC)
2 Information Way
Bethesda, MD 20892-3570
301-654-3810
http://www.niddk.nih.gov

National Foundation for Infectious Diseases
4733 Bethesda Avenue, Suite 750
Bethesda, MD 20814-5228
301-656-0003

OTHER IMPORTANT WEB SITES:

California Department of Health Services
http://www.dhs.ca.gov/ps/dcdc/html/publicat/htm

Children's Liver Alliance
http://livertx.org

Department of Veterans Affairs
http://www.va.gov/hepatitisc/

Hepatitis C Support Project
http://hcvadvocate.org

HIV and Hepatitis
http://www.hivandhepatitis.com

United Network for Organ Sharing
http://www.unos.org

FACTS ON HEPATITIS C FROM THE CDC

SIGNS & SYMPTOMS

80% of persons have no signs or symptoms.

- jaundice
- fatigue
- dark urine
- abdominal pain
- loss of appetite
- nausea

CAUSE

Hepatitis C virus (HCV)

LONG-TERM EFFECTS

Chronic infection: 75-85% of infected persons
Chronic liver disease: 70% of chronically infected persons
Deaths from chronic liver disease: <3%
Leading indication for liver transplant

TRANSMISSION

Recommendations for testing based on risk for HCV infection

- Occurs when blood or body fluids from an infected person enters the body of a person who is not infected.
- HCV is spread through sharing needles or "works" when "shooting" drugs, through needlesticks or sharps exposures on the job, or from an infected mother to her baby during birth.
- Persons at risk for HCV infection might also be at risk for infection with hepatitis B virus (HBV) or HIV.

*Anyone who wants to get tested should ask their doctor.

RECOMMENDATIONS FOR TESTING BASED ON RISK FOR HCV INFECTION

PERSONS	RISK OF INFECTION	TESTING RECOMMENDED?
Injecting drug users	High	Yes
Recipients of clotting factors made before 1987	High	Yes
Hemodialysis patients	Intermediate	Yes
Recipients of blood and/or solid organs before 1992	Intermediate	Yes
People with undiagnosed liver problems	Intermediate	Yes
Infants born to infected mothers	Intermediate	After 12-18 mos. old
Healthcare/public safety	Low	Only after known workers exposure
People having sex with multiple partners	Low	No*
People having sex with an infected steady partner	Low	No*

*Anyone who wants to get tested should ask their doctor.

FACTS ON HEPATITIS C FROM THE CDC

PREVENTION

- There is no vaccine to prevent hepatitis C.
- Do not shoot drugs; if you shoot drugs, stop and get into a treatment program; if you can't stop, never share needles, syringes, water, or "works", and get vaccinated against hepatitis A & B.
- Do not share personal care items that might have blood on them (razors, toothbrushes).
- If you are a health care or public safety worker, always follow routine barrier precautions and safely handle needles and other sharps; get vaccinated against hepatitis B.
- Consider the risks if you are thinking about getting a tattoo or body piercing. You might get infected if the tools have someone else's blood on them or if the artist or piercer does not follow good health practices.
- HCV can be spread by sex, but this is rare. If you are having sex with more than one steady sex partner, use latex condoms* correctly and every time to prevent the spread of sexually transmitted diseases. You should also get vaccinated against hepatitis B.
- If you are HCV positive, do not donate blood, organs, or tissue.

TREATMENT & MEDICAL MANAGEMENT

- HCV positive persons should be evaluated by their doctor for liver disease.
- Interferon and ribavirin are two drugs licensed for the treatment of persons with chronic hepatitis C.
- Interferon can be taken alone or in combination with ribavirin. Combination therapy is currently the treatment of choice.
- Combination therapy can get rid of the virus in up to 4 out of 10 persons.
- Drinking alcohol can make your liver disease worse.

STATISTICS & TRENDS

- Number of new infections per year has declined from an average of 240,000 in the 1980s to about 40,000 in 1998.
- Most infections are due to illegal injection drug use.
- Transfusion-associated cases occurred prior to blood donor screening; now occurs in less than one per million transfused unit of blood.
- Estimated 3.9 million (1.8%) Americans have been infected with HCV, of whom 2.7 million are chronically infected.

* The efficacy of latex condoms in preventing infection with HCV is unknown, but their proper use may reduce transmission.

Important resource on Hepatitis C, refer to the Centers for Disease Control publication entitled - Recommendations for Prevention and Control of Hepatitis C Virus (HCV) Infection and HCV-Related Chronic Disease. MMWR Recommendations, available on their web site at http://www.cdc.gov/ncidod/diseases/hepatitis/resource/pubs.htm.

NOTES