
a series of fact sheets written
by experts in the field of liver
disease

HCV Advocacy:
***Advocates and
Activists Needed!***

Alan Franciscus, Editor-in-Chief

ADVOCACY AND ACTIVISM ARE TERMS THAT ARE sometimes confused because the roles they entail can be similar and often overlap. Activism is defined as the theory or practice of assertive – often militant – action, such as mass demonstrations (or strikes) as a means of opposing or supporting a controversial issue, entity or person. Advocacy is defined as the act of actively supporting, that is, pleading or arguing in favor of something, such as a cause, an idea or a policy.

Generally, when we think of activists, we think of people who are strongly assertive and demand immediate change. What generally comes to mind are civil rights activists, antiwar activists and AIDS and breast cancer activists. In the case of these movements, there has been an undeniable need for immediate change. These dedicated individuals have spoken out and sometimes put their lives on the line to bring about social, economic, medical and other necessary changes.

Activism and advocacy have taken many forms in the past. One of the first large-scale successes in modern history was achieved by Mahatma Gandhi in his quest to gain the independence of India from Great Britain by direct, non-violent confrontation. The Reverend Martin Luther King, Jr. was able to draw from Gandhi's experience to challenge discrimination against African

Americans in this country when he led the civil rights movement in the 1960s. In more recent times, AIDS activists have been able to use similar strategies to bring about much needed change for people living with HIV and AIDS. In fact, the AIDS activist movement, which developed in the late 1980s, was the first illness-related group to adopt non-violent, direct action to bring about social change. Since that time, other disease-related causes, such as the breast cancer awareness movement, have been able to learn from these activist/advocacy groups and have brought about changes using similar techniques.

Unfortunately, at this time, the HCV community has only a handful of activists in the U.S. who are trying to bring about greater awareness, more services and better care for people affected by HCV. Many of these activists have previously been involved as AIDS activists – many still are, fulfilling a dual role in their work in needle exchanges and other harm reduction-oriented agencies and programs – and are mentoring and joining the ranks of HCV activists. On the other hand, there are many HCV advocates across the nation. These individuals are mainly HCV-positive individuals who have been moved to respond to the lack of awareness and services on the part of the government and other agencies.

The HCV activist/advocacy community emerged in the mid-1990s to tackle many issues that had been largely ignored by the government and the public sector. The Hepatitis C Support Project, the Hepatitis Support and Education Project, Hep C Connection and many others emerged to advocate for the HCV community by supporting and educating both people with HCV and the general public. Simultaneously, programs working to prevent the spread of HIV in injecting drug users, like the Lower East Side Harm Reduction Program, the UFO Project and the Harm Reduction Coalition, realized the extent of HCV infection in this population and began work to curtail the spread of hepatitis C among IDUs and to ensure they had access to up-to-date-information on treatment and prevention.

As knowledge of HCV has increased, and the organizations that work on the related issues have matured, there has been an accompanying increase in the need to advocate for specific populations with HCV, such as prisoners, and particular issues, like access to affordable drugs.

There are many organizations and dedicated individuals who have given selflessly of their time and energy to help bring about greater awareness and more services for the HCV community. However, many more are required to bring about needed improvements in care and services.

Most people believe that it is difficult and time-consuming to be involved in activism or advocacy. This is true for some efforts, but there are many actions that require little time or involvement. An important aspect of activism or advocacy is that it can help those with HCV feel that they can take control of their lives and effect change that benefits both the individual and the community as a whole. In addition, people from every economic, social, racial and political group are needed for fair representation.

What You Can Do

Educating Individuals and the Public

As they say, information is power, and people who educate can move mountains. Learn as much as you can about HCV and educate people and organizations, where appropriate. Make sure you know your facts and pick your fights carefully. Be prepared to back up your views with solid facts, and have copies of reports or studies available to hand out. Government officials (including those working in public health) have immense power, and access to a lot of money. Look at the work U2's Bono has done with Jesse Helms. By enlightening Helms on the impact of AIDS in Africa and other impoverished areas, the one-time foe of AIDS funding turned into an advocate for it – not just in the Third World, but in the US, too.

Health Departments / CDC Hepatitis C Coordinators

Contact and support your local health department and

the local CDC Hepatitis C Coordinator. Impress upon them that HCV is an important issue and ask if you can help them in any of their efforts.

To contact your state hepatitis C coordinator go to www.hcvadvocate.org/hepatitis/hepC/hepatitis_coordinators.html

Accountability

Public health departments, community based organizations and elected public officials are accountable to their local constituents. Make your voice heard, but it is important to offer help and work with any agency that is willing to move the HCV agenda forward.

Support Groups

HCV support groups were one of the first results of advocacy efforts to emerge. A support group setting can help people with HCV learn about the disease, coping strategies and other important issues. Starting and continuing a support group can be one of the best steps you can take to advocate for the community.

Helping Individuals / Patient Advocacy

Helping others can be a very rewarding experience, whether it's something you take on as an individual, or in a more formal capacity, as part of your work at a service agency (patient advocacy). Many people with HCV have numerous unmet needs. It may not seem like much, but simply listening, running errands, helping sort through insurance issues or accompanying someone to a medical appointment can be a tremendous help. If you decide to take on this type of responsibility, be sure to define your role in the relationship from the beginning. It is also important to make sure that you can carry out any commitments you make.

Create Educational and Training Materials

This is especially important when working with stigmatized groups like injection drug users and prisoners. Creating and distributing educational materials gets crucial information out to the people who need it, and can also help stimulate changes in policy and clinical practice, as service providers come into contact with new ideas, and stereotypes are challenged. Training

can help ensure the replication of such state-of-the-art work.

Political Advocacy

Involvement in local and national politics can have a tremendous impact. Check with your local city or county health department or agency and attend meetings addressing HCV-related issues. Putting together a petition to submit to a local government can be highly effective. Become involved and know your local candidates; send them letters about issues that affect the community.

An example of effective political advocacy is the campaign to have the NIH HCV consensus statement amended, ending the current recommendation to refuse treatment to anyone who has not been abstinent from drugs or alcohol for at least six months. A letter signed by many prominent community advocates, researchers, public health specialists and clinicians was presented at the 2002 Consensus Development Conference on Management of Hepatitis C to the authors of the new statement. Additionally, supporters of the revisions presented research to support the requested changes. As a consequence of these efforts, the new version of this statement says that “many patients with chronic HCV have been ineligible for trials because of injection drug use (IDU), alcohol abuse, age, and a number of comorbid medical and neuropsychiatric conditions. Efforts should be made to increase availability of the best current treatment to these patients. Because a large number of HCV-infected persons in the United States are incarcerated, strategies should be developed to better prevent, diagnose, and treat these individuals.”

The Viral Hepatitis and Liver Cancer Control Act (H.R.3974)

The Viral Hepatitis and Liver Cancer Control Act would amend the Public Health Service Act to establish, promote, and support a comprehensive prevention, research, and medical management referral program for chronic hepatitis B and chronic hepatitis C virus infection, to include the following:

- Education and training
- Medical referral

- Hepatitis B and C disease control
- Surveillance
- Immunization
- Research
- State health department adult viral hepatitis coordinators
- Integration with existing programs

Expanded access to services for underserved and disproportionately affected populations

The Viral Hepatitis and Liver Cancer Control Act is in need of your support. Call, write and fax your local and state representatives recommending that they support the bills. It is important that your congressperson and senator know that you support this bill. Your senator or congressperson is well aware of the political pressure since they are elected by and accountable to you.

For more information on the **Viral Hepatitis and Liver Cancer Control and Prevention Act of 2009 (H.R.3974)** and how to advocate for this important legislation go to the National Viral Hepatitis Roundtable (NVHR) at www.nvhr.org

Direct Action

AIDS activists pioneered the use of direct action to influence government officials, drug companies, religious leaders and others. Such actions have included demonstrations to influence public opinion, confrontations with government agencies such as the National Institutes of Health to demand more research, and visits to drug companies to demand lower prices. HCV activists have followed this lead, for example, by calling for better care for people with HCV in prisons and demanding reduced prices and unbundling of HCV drugs.

Community Advisory Boards / Committees

A community advisory board is a group of individuals who represent a community and provide informed recommendations, for example, to a pharmaceutical company or a research team. Local governments,

private companies and charitable organizations often have committees that can benefit from the input of members of affected communities. The level of involvement required varies from group to group. Sometimes a voice from the community is all that is needed, but other boards and committees demand a great deal of time and energy. Do your homework ahead of time and take your responsibilities seriously. Remember that you represent the community, and act accordingly.

Media

Enlist the help of the media by developing a press kit on hepatitis C that you can send to various news services in your area. The media is very powerful so it is important that you start to craft your message and develop a relationship with your local media.

HCV Task Force

Start or work with a local community task force on hepatitis C. A task force can have a tremendous impact on local services and support for the hepatitis C community.

We can all make a difference in our own way. Many times, I have heard people remark that one person cannot possibly make a difference. This type of sentiment could not be further from the truth. In my advocacy work, I have met extraordinary people who have taken action and made remarkable progress in bringing about more awareness, education, and improvement in the quality of life for people with HCV. Are you ready for the challenge? You can make a difference – all you need to do is to make an effort and follow your heart.

Resources

- **Hep C Advocate United** is a grassroots coalition formed by concerned HCV organizations, people living with hepatitis C and concerned citizens. This national network of advocates work together to increase awareness, funding, hepatitis programs and legislation. To join send an email to RClary@projectinform.org with "Subscribe" in the subject field. In the email please include your first name (last name is optional) and your city/state.

- **The National Hepatitis C Advocacy Council** was formed in an effort to bring together the collective strengths of hepatitis C patient advocacy organizations. To learn more visit their Web site at www.hepcnetwork.org

- **The National Viral Hepatitis Roundtable (NVHR)** is a national organization consisting of various viral hepatitis agencies dedicated to developing, implementing and maintaining a national strategy to eliminate viral hepatitis in the United States. Visit their Web site at www.nvhr.org

- **Adult Viral Hepatitis Prevention Coordinator List**
<http://www.cdc.gov/hepatitis/Partners/Adult/AdultHepCoordList.htm>

- **Locate a Support Group:**
<http://www.hcvadvocate.org/community/Groups.asp>

For more information about hepatitis C, hepatitis B and HCV coinfections, please visit www.hcvadvocate.org.

• *hcsPFACTsheet* •
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