THE HEPATITIS PATIENT REGISTRY NETWORK [HEPPRN]

ENGAGING INDIVIDUALS ... FINDING SOLUTIONS... SAVING LIVES

Hepatitis Foundation International
800-891-0707
www.HepatitisFoundation.org/patientregistry
WHO IS THE HEPATITIS FOUNDATION INTERNATIONAL (HFI)?

- HFI is a 501 (c) 3 non-profit organization established in 1994 working to eradicate chronic hepatitis for 500 million people globally. HFI is also dedicated to increasing and promoting health and wellness, as well as, reducing the incidence of preventable liver-related chronic diseases and lifestyles that negatively impact the liver.

- HFI implements its mission through our touchstones to educate, prevent, serve, support and reach over 5 million patients and health care professionals annually through our public and private partnerships.

- For more than 20 years HFI has worked to develop critical education and information about viral hepatitis to our constituents nationally and globally.
WHAT IS THE HEPATITIS PATIENT REGISTRY (HepPRN)?

• A highly secure web portal

• A patient-centric survey collects health data from you and other people living with hepatitis and other liver-related conditions

• The survey is focused on what it is like to live with hepatitis

• The Hepatitis Foundation International (HFI) developed the HepPRN survey
HOW DID HFI CREATE THIS VALUABLE ASSET?

- Through a partnership with Genetic Alliance as part of a larger project called CENA.
- Community Engaged Networks for All (CENA) includes nine other disease advocacy organizations serving different conditions.
- CENA is one of 29 projects funded by the Patient Centered Outcomes Research Institute (PCORI) to form a new national resource that will accelerate health research.
- CENA uses highly secure technology called, Platform for Engaging Everyone Responsibly (PEER), developed by a highly reputable medical information security company, called Private Access.
- PEER collects your information and provides you with control as to who can access your data and for what purpose.
WHAT ARE THE NEEDS ADDRESSED BY HepPRN?

- Expands on previous information collected via HFI’s Hepatitis Hotline
- To investigate which therapies are working for you
- To identify symptoms we haven’t associated with hepatitis before
- To increase interest in research for hepatitis
- To save lives, reduce or eliminate hepatitis
- To learn of undiscovered relationships to other liver related diseases
- To find the best way to identify and locate undiagnosed people
- To reach out and gather data from minority communities, other underserved communities that have not been fully represented in research
- To help find resources in your communities
- To help patients understand coping mechanisms
WHAT IS THE FOCUS OF THIS SURVEY?

• HepPRN is as broad as we could make it because we have never done a registry before.

• We are also asking some non-medical questions about quality of life.

• We are very interested in learning about symptoms we didn’t know about before.
WHO HAS ACCESS TO THE INFORMATION I PROVIDE?

You are in control! You set who has access and for what purpose through your settings.

Potential data users were set by the Hepatitis Foundation International and include the National Institute of Health (NIH) and the Centers for Disease Control and Prevention (CDC).
An institutional review board (IRB), also known as an independent ethics committee or ethical review board, is a committee that has been formally designated to approve, monitor, and review biomedical and behavioral research involving humans.

They often conduct some form of risk-benefit analysis in an attempt to determine whether or not research should be done.
The number one priority of IRBs is to protect human subjects from physical or psychological harm. In the United States, the Food and Drug Administration (FDA) and Department of Health and Human Services (specifically Office for Human Research Protections) regulations have empowered IRBs to approve, require modifications in planned research prior to approval, or disapprove research.

IRBs are responsible for critical oversight functions for research conducted on human subjects that are "scientific," "ethical," and "regulatory."
SPECIFIC RESEARCHERS CHOSEN FOR HepPRN BY HFI

- National Institute of Health (NIH)
- Centers for disease control and prevention (CDC)
- Health and human services (HHS)
- Office of minority health (OMH)
- American Association of the study of liver diseases (AASLD)
- And many more to come
Disease InfoSearch is a Disease database powered by Genetic Alliance with over 13,000 organizations listed.

Organizations are screened by Genetic Alliance in order to be listed.

They include other organizations that serve people with your condition and organizations serving people with symptoms that can be related to hepatitis.
HOW DO I CONTROL WHO GETS MY DATA?

- The secure platform we use, designed by Private Access, provides you with **control** over your settings.

- Choosing your settings is **very easy** - you don’t need to be a computer whiz to do it!

- We have provided you with guides (Ivonne, Fuller, CEO of HFI; Karen Wirth, Patient Advocate and Chair of HFI Board; and LeighAnn Vogel, Survivor and Patient Advocate) to show you how to choose your settings. You will find the guides and their recommendations inside the survey.
HOW MUCH CONTROL DO I HAVE?

This graph shows Public Views on privacy and health research. Where do you fall in this scale? You will find this in the survey along with what your guides recommend.

Given your attitude about sharing information, where would you place yourself along the spectrum at the bottom of this chart.*

- 1.5%: Okay for researchers to use my data without my consent at all...
- 10%: Willing to give general consent in advance for use of my data without being contacted...
- 24%: Consent is not needed if my identity will never be revealed and the study is IRB supervised...
- 48%: Want each study seeking to use my data to contact me in advance and to get my specific consent each time...
- 16.5%: I would not want researchers to contact me or to use my data under any circumstance...

< concern for Access  concern for Privacy >

* Underlying chart and statistical results based on the study commissioned by the Institute of Medicine (2009) and conducted by Dr. Alan F. Westin. The percentages shown reflect the views of those persons expressing an opinion. An additional 20% of the persons surveyed indicated that they were “Not sure.”
YOU CAN ALSO CHOOSE TO BE ASKED TO PARTICIPATE IN RESEARCH

• Some research studies will look for participants
• You can choose a selection that allows a researcher to contact you to participate
WHY SHOULD YOU BE INVOLVED?

• You have a voice, finally!
• Others before you provided the information we have today that you benefit from having – now you can “Pay it Forward”
• Our clinics need this data to help you
• We could investigate new research we never imagined
• You have shared your stories with one another, now let’s share it with those who can help us
• More people could be accurately diagnosed
WHY SHOULD YOU BE INVOLVED?

• We could find new treatments that make all the difference

• Discoveries could be made linking our issues with others, solving our problems and others as well

• We could eliminate this condition or significantly reduce its impact

• We could reduce the impact this condition is having on our family members

....and many many more reasons to take the time to do it
Our survey takes 60-90 minutes if you answer all of the questions.

HFI wants you to know that this is the very BEST use of your time. Give up a little of your support group time for it.

Treat this like something on your schedule. Set a day and time when you will do it. You can also start it and finish it in different sittings.

If you need help, we have trained navigators to walk you through getting started.
GOT QUESTIONS?

If you have questions or need assistance, please visit www.hepatitisfoundation.org to contact us at 1-800-891-0707.
DID WE HEAR YOU SAY THAT YOU WANT TO DO MORE TO HELP?

If you want to help to make this a huge success for you and everyone, help us by:

• Spreading the word through all of your networks including social media. Follow us on Twitter @HFIconnect and Facebook for material! Also follow @CENAProject!

• Talking it up! Let people know how easy it is!

• Sending some emails about it to your friends in the group
DID WE HEAR YOU SAY THAT YOU WANT TO DO MORE TO HELP?

• Printing out some of our flyers and bringing them to your doctor’s office, support group meetings or conferences

• Contacting us about guest blog posts we have at the ready if you have a blog

• Sending an email to your online support groups

• Remember there are eight other organizations in our larger project. If you belong to large support groups covering different conditions, tell the group about all of the organizations involved. They are listed on the Genetic Alliance Website. http://www.geneticalliance.org/programs/biotrust/cena
We want to know what works...

We have added “referral codes” to every method of communication we are using to spread the word on this project. The codes help us to understand what messages are motivating people to get involved.
READY, SET, GO!

➢ Go to our website: www.hepatitisfoundation.org/patientregistry

➢ Click on Start HepPRN Survey

➢ Use referral code: WEBINAR
THANK YOU IN ADVANCE FOR PARTICIPATING

Your effort will ripple well into the future